

**NARRATIVES OF SEPARATION: INSTITUTIONS, FAMILIES, AND THE
CONSTRUCTION OF DIFFERENCE**

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Abstract

Parents of children with intellectual disabilities born in Ontario in the era following World War II found themselves obliged to make significant yet misinformed decisions regarding their child's long-term care. Immersed in postwar discourse which promoted the normative construction of the Canadian family, in combination with limited community support and generalized misconceptions of intellectual disability, many families had to choose between two principal options: keep their child at home and raise a child with needs divergent from the "norm" with few resources, or place the child in a segregated institution. Dating back to the latter half of the mid-nineteenth century, large-scale institutions for people with intellectual disabilities had become the predominant model of care for people with intellectual disabilities in Ontario outside of the family home. Many thousands of individuals were admitted to institutions; this bore significant consequences both for those admitted and for the families who decided to send them there. To date, scholarly work on institutions has focused on historical, political, and social factors which contributed to their development, as well as the more recent address of the narratives and histories of people who have lived there. Little is known, however, about the effect on family relationships and understandings of disability when one member of the family is institutionalized. The purpose of this project is to explore family relationships and understandings of disability when a family member with an intellectual disability is institutionalized for an extended period of time. Its principal body of data stems from thirty-six in-depth interviews conducted with the members of several families, including parents who institutionalized their children, siblings of those institutionalized, and those who were themselves institutionalized in Ontario in the years following World War II. Family members had widely divergent experiences in regards to institutionalization processes. Interpretations of the impact

institutionalization had on the family were dependent on one's location in relation to institutionalization. Findings demonstrate how relations of power were manifested in the family through institutionalization processes, and show the significant role that discursive constructions of intellectual disability have had on participants' understandings of disability and of their family member.

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Part I

Introduction

Parents of children with intellectual disabilities born in Ontario in the era immediately following World War II found themselves obliged to make significant yet ultimately misinformed decisions regarding their child's long-term care and welfare (Simmons, 1982; Williston, 1971). Confronted with social and political discourse shaped by middle-class "postwar optimism and the boom economy" (Trent, 1994, p. 239), a discourse which promoted the normative construction of the Canadian family and raising "the right kind of children" (Helleiner, 2001, p. 149), many families with a child with a disability felt isolated, ostracized, and uncertain how to best care for their child (Dolmage, 2011; Panitch, 2008). These factors, in combination with limited community and financial supports and generalized misconceptions of disability, meant that families had to choose between the two principal options which existed at the time: keep their child at home and venture into a life-long commitment of raising a child with needs divergent from the norm with few resources and little acknowledgement of both the demands and benefits this might bring to a family, or place the child in a segregated institution (Panitch, 2008; Simmons, 1982). Despite increasing recognition during the postwar era of the fundamental human rights inherent to all peoples and the need to enact access to those rights (Simmons, 1982), placing a child with a disability in an institution remained a viable and acceptable option within the public arena such that admissions to long-term, segregated institutions for people with intellectual disabilities in Ontario continued to rise (Radford & Park, 2003; Simmons, 1982; Williston, 1971).

Dating back to the previous century with the establishment of the Orillia Asylum for Idiots [*sic*] in 1876, institutions were long embedded in Ontario's response to the 'problem' of

people with intellectual disabilities. Originally designed to meet the “demand for accommodation” (Simmons, 1982, p. 27) for people increasingly being identified as ‘feeble-minded’, the Orillia asylum also supported political motives at the time to separate variant forms of deviance, and to “alleviate pressure for space on local jails and the main asylums” (ibid). Moreover, the proliferation of eugenic (McLaren, 1990) and xenophobic (Chadha, 2008) ideology during the era of intense settlement and nation-building in the early part of the twentieth century (Baynton, 2011), including the intellectual and political conflation of people with “mental deficiencies” (Chadha, para 6), “defective aliens” (McLaren, 1990, p. 46) people accused of criminal behaviour, the “insane” (Menzies, 1998), and all manner of “deformed, subnormal, and undernourished” individuals (Sanger, M., as cited in Lamp, 2006, para 24), all contributed to the further development of institutions in Ontario (as well as in other parts of Canada and the United States), and to the political and financial motive to fill them (Radford & Park, 1993a). Thus, despite historical fluctuations in socio-political discourse concerning the purpose of institutions and whose needs they were actually designed to meet, the institution became ensconced as the predominant model of care for people with intellectual disabilities in Ontario outside of the family home well into the twentieth century, and remained in existence until the final closure of all institutions in March 2009. The predominance of institutional care in Ontario resulted in many thousands of individuals being admitted into their purview, and bore significant consequences both for those admitted and for the families who decided to send them there.

To date, much of the scholarly work on institutions and institutionalization practices has focused on historical, political, and social factors which have contributed to their development. Indeed, the historical canon is rich with analyses that highlight material and economic influences

(see, for example, Rothman, 1980, 1971; Scull, 1983, 1979), the influence of disciplinary, judicial, and governing mechanisms on the development of institutions (Foucault, 1977, 1965), and the role that institutions have played in the segregation of populations of people historically feared for their difference (Goffman, 1961; Hubert, 2000b; Radford, 1991; Radford & Park, 1993a). Moreover, scholarly work in disability studies has begun to address the narratives and histories of people who have lived in Canadian institutions (see, for example, Broderick, 2011; Jones, 1992; Malacrida, 2006, 2005; Odell, 2011; Reaume, 2000). To date, however, little work has been done on the effects of institutionalization on families who participated in this phenomenon. While there is a large body of work from rehabilitation and social work canons which focus on the (assumed negative) impact of the disabled child on the functioning of the family, work which consistently situates the child with the disability as the problem (see, for example, Bailey et al., 2006; Blacher et al., 2005; Blackard & Barsch, 1982; Davis, 1980; Dew et. al., 2008; Freedman & Boyer, 2000; Jones & Passey, 2004; Lobato, 1983; McHale et. al. 1986; Meaden et. al.; Orsmond & Seltzer, 2009; Reichman et al., 2008; Rodger, 1985; Sherman & Coccozza, 1984), little is known about the effect on family relationships and understandings of disability when one member of the family is institutionalized for an extended, often permanent length of time. It is this rupture in family history and understanding that is the principal focus of this study.

The purpose of this project, therefore, is to explore family relationships and understandings of disability when a family member with an intellectual disability was institutionalized for an extended period of time. While this necessarily involves an examination of historical and social conditions which contributed to the continuation of institutional care in Ontario, as well as motivating factors towards institutional placement, the study's principal focus

is to examine the impact of institutionalization on families when a family member who was identified as having an intellectual disability was institutionalized. Qualitative in nature, the project has been informed by work from various fields, including historical and geographic analyses of institutionalization (see, for example, Chouinard et al, 2010; Dorn, 1999; Parr, 1999; Radford, 1991; Radford & Park, 2003, 1993b; Reaume, 2006, 2004, 2000; Park & Radford, 1999; Stiker, 1999), analyses of the socio-political discourse which influenced families' decision-making in regards to institutional placement (Brookfield, 2012; Gleason, 1999a, 1997; Helleiner, 2001), and anthropological and psychological reflections on the historic need to identify and segregate people with corporeal and intellectual differences (Goffman, 1961; Hubert, 2000a, 2000b; Kristeva, 1982; Douglas, 1966). Its principal body of data, however, stems from thirty-six in-depth interviews conducted with the members of several families, including parents who made the decision to institutionalize their children, siblings of those institutionalized, and those who were themselves institutionalized in Ontario in the years following World War II. While families took priority in the project, interviews with former staff at Ontario institutions and from key informants were also included.

Reflections from family members who participated in this project indicate a range of experiences and interpretations, suggesting that one's experience of institutionalization is highly dependent on one's location in relation to its direct manifestation. For example, the sadness, anger and revulsion with which all of the survivors recalled their time in an institution is vastly different from the relief that some of the parents indicated was their primary emotional response to their child being placed there. Further, the anger which many of the siblings felt towards their parents for having removed a brother or sister from the family home did not figure prominently in parents' recollections of the effect that placing a child in an institution had on the rest of the

family. Vastly removed from each other in location and experience, different members of the same family ascribe completely different meanings to what was essentially a shared experience.

Yet the divergences in experience do not end in disconnected and dead-end observations. Rather, these divergences point instead to common themes which emerged between all groups of participants. Indeed, it is the disconnect between various peoples' experiences that illuminates broad, underlying themes of significant import, differentiated not by content, as all participants experienced a significant separation, but by the experience of and meaning ascribed to that separation. These themes include in particular how relations of power were conducted through the enactment of institutionalization in the family, and the extent to which discursive constructions of intellectual disability influenced participants' understandings of disability. That is, the different meanings that people ascribed to factors influencing the decision to institutionalize, as well as the impact that these decisions had on the family, were deeply connected to the amount of power held by particular people in the family constellation and how power was conducted through various relationships. Further, the tension between essentialist and constructivist interpretations of disability emerged consistently between various groups of participants. That is, those who determined that intellectual disability is an innate and measurable condition requiring a particular kind of care were likely to frame the institution as a beneficial and necessary entity; those who recognize the historical influences on the construction of disability were far more likely to question their purpose. While the tension itself is an indication of divergent experiences and interpretations, it was also a consistent and binding feature between the various groups. These two principal themes, as well as those which emerged specifically from within each group of participants, are discussed in greater detail in the findings and analysis chapters in the second half of the dissertation.

The dissertation is divided into two main sections. Part I consists of five chapters and provides a detailed historical and contextual background to the development of institutions both generally and in Ontario as well as factors that contributed to families' decisions to institutionalize. Chapter One provides a theorisation of institutions. In particular, I examine the symbiotic and mutually-sustaining relationship between the development of institutions and what Rhodes (2001) refers to as "the compulsive temporal and spatial arrangements of modernity" (p. 69). This analysis necessarily reflects on the influences of Kant and Weber, and acknowledges the contributions of Foucault, Scull, and Rothman in their distinct assessments of the impulses that shaped the development of institutions in regards to disciplinary, materialist, and stabilizing mechanisms respectively. Chapter One also examines the notion of institutionalization as an embodied phenomenon as has been theorized by scholars from feminist, psychological, and anthropological perspectives.

Chapter Two provides a broad overview of the historical and contextual factors which contributed to the development of institutions for people with intellectual disabilities. This includes discussions on the role of charitable impulses; the development of intelligence testing and the resultant ranking of individuals according to perceived 'value'; and the rise of eugenic thinking and policy, all of which contributed to the establishment of segregated sites for the containment of the 'feeble-minded' in the latter half of the nineteenth and early part of the twentieth centuries. This chapter in particular demonstrates the susceptibility of disability to shifts in its discursive construction which have historically had profound influence on social responses to people designated as intellectually impaired.

Chapters Three and Four continue the discussion initiated in chapter Two and outline the historical development of institutions for people with intellectual disabilities specific to North

America and Ontario respectively. These chapters provide a chronology of institutional development, and remark upon the shift from the ‘good’ but misguided intentions of the earliest forms of custodial care in the United States based on rehabilitation and training, to models which, at their peak, did little more than perpetuate the segregation of thousands of people. Chapter Four also notes Simmons’ (1982) “palimpsest” (pp. 41-48) model of institutional development which suggests that Ontario’s response to people with intellectual disabilities has historically been a politically-driven reaction to other perceived ills embedded in the social fabric, as opposed to a response to the needs of people with intellectual disabilities.

Chapter Five addresses the social, political, and cultural conditions specific to post World War II Canada, the time period with which this study is concerned, and the influence these conditions had on the discursive shaping of disability within the public arena. In particular, it examines how ubiquitous cold war notions of ‘containment’ and ‘threat’ contributed to a culture of strict normativity that influenced the re-emergence of traditional gender and familial roles, all of which contributed to definitions of intellectual disability as a deviant condition, and contributed to families’ decisions to institutionalize.

Part II of the dissertation contains the heart of the research. Chapter Six, the methodology, outlines the specific steps taken to gather the primary and secondary data for this study. In this chapter, my theoretical perspective, the orienting lens that I adopted for the study, as well as ethical considerations are all outlined, along with data collection and analysis techniques. Chapters Seven to Eleven are the reports of the findings from each of the five groups of participants: survivors, siblings, parents, former staff, and key informants. While analyses of the findings are undertaken as they are detailed, a summative analysis which attempts to draw together recurrent themes from all groups is provided in Chapter Twelve.

At this point, some discussion regarding language is necessary. There has been much discussion in the disability studies literature regarding the most appropriate language to be used when discussing the history and concerns of people with disabilities. For the most part, debate has centred on the distinction between ‘impairment’ and ‘disability’ (see, for example, Barnes, Mercer & Shakespeare, 1999; Hughes & Paterson, 1997; Shakespeare, 2006, Thomas, 2002, 1999; Williams, 2001), on the potency of self-naming (Bersani, 1996) and whether ‘people-first’ or ‘disability-first’ language is the most appropriate when speaking from the perspective of people with disabilities (Bersani, 1996; Linton, 1998). Moreover, debate exists regarding the use of terminology which has historically been used to categorize and ultimately oppress and degrade people with disabilities, including terms relevant to this study, such as *mentally retarded* and *feeble-minded*. Carlson (2005), in her work on the “status of mental retardation as a classification” (p. 133), states that she utilizes the term *mental retardation* “deliberately” (p. 150, endnote 1) in order to provoke discussion around such terminology as “a historically constituted category” (ibid). Indeed, our understanding of the nature of the discrimination directed against people with disabilities at various points in our history must include an awareness of the language that was used during those time periods, particularly in light of the historical interrelationship between linguistic constructions and the perception of people with disabilities. Accordingly, terminology no longer in use (although unfortunate examples of derogatory language being directed at people with disabilities continue to exist) due to its discriminatory and oppressive nature is generally avoided in this project, except to reflect on its use within a particular time period. Further, every effort has been made to use people-first language throughout the text, as I interpret it as the best nomenclature we have thus far in our history to refer to groups of people who have historically suffered because of categorical distinctions,

reinforced through linguistic means. At times, ‘disabled people’ or ‘intellectually disabled person’ may appear for convenience’s sake. In general, I have chosen the term ‘intellectual disability’ to denote the group of people in this study who experienced institutionalization, as this is the term currently in use in Ontario¹. I take full responsibility for any language used in this project which inadvertently refers to people with disabilities in a less than inclusive, just, or non-oppressive manner.

Further, I state here my preference regarding social constructivist interpretations of disability, a stance which is further clarified in the methodology chapter of this dissertation. Similar to comments above regarding language debates, contention remains within the disability studies community and beyond regarding the limits to which the notion of a purely social constructionist approach to disability can be realized (Hughes & Paterson, 1997; Shildrick, 2009). However, I have adopted a social constructivist perspective in this work after reflection on the findings which suggest that much of the impulse towards the classification and eventual segregation of people designated as intellectually disabled arose through essentialist understandings of disability, wherein the powerful effects of discourse on people’s lives were not acknowledged, nor even realized. Therein lies a critical piece of this work: that the shifting definitional boundaries of intellectual capacity have been used to define and dictate the direction of people’s lives, in particular, where they might live and with whom they might forge relationships.

Last, before I embark into the heart of this project, I will address the notion of reflexivity in the research process. As feminist scholars such as England (1994), Lather (1991), and Stanley & Wise (1993), as well as disability scholar Vernon (1997) have indicated, it is vital to situate my own interest in this research and to frame my reasons for its undertaking. While I have had

extensive involvement with people with intellectual disabilities for well over two decades in the role of friend, worker, and advocate, the direct inspiration for this project stems from a funeral. Four years ago, I attended the funeral of a man who had lived most of his life at the Huronia Regional Centre, a huge, government-run facility for people designated as intellectually disabled located in Orillia, Ontario. For the last seven years of his life, however, this man lived at home in the community, a home in which he lived a full life, with meaningful work, friendships, and an active social circle. He had come from a large family, and his siblings were in attendance at his funeral. There, I was struck by what appeared to be looks of consternation on the faces of his many brothers and sisters. While I cannot presume to know what these siblings were thinking or feeling during those moments, I could not help but think that they were experiencing a disconnect between what they had been told about their brother—a young, ‘retarded’ [sic] boy who had been sent away from home at a very young age because he could not live at home any more—and what they were now observing in the celebration surrounding his life and all that he had brought to the community around him. Could this, in their eyes, be the same boy? My reflection on their apparent disconnect led me to the guiding questions which surround this research, that is, to explore the impact that institutionalization had in the lives of families, not only on those sent to live there, although that phenomenon alone warrants deep and unflinching interrogation, but also on those who carried on at home in its wake. More personally, this project stems from my own desire to explore even just one facet of lives that have been touched, regrettably, by a historical process instituted and sustained because of the presumed deficits of difference.

This project is, in many ways, a historical piece undertaken by a non-historian. Indeed, the impulse to investigate this particular phenomenon stemmed not only from curiosity about its

historical unfolding, but from a desire to understand the public and private manifestations of institutionalization practices in people's lived experiences. It originates from the premise that it is important to explore what it really meant to live a family life marked by significant separation caused, among other reasons, by particular interpretations of intellectual disability, a process that necessarily involves some degree of historical excavation. Within this mandate, we are allowed a view of practices which oppressed many thousands of people for over one hundred years, and to gain a glimpse of its direct materialization in people's lives.

Chapter One: Theorising institutionalization

Introduction

From a broad perspective, institutions are enduring political or social structures and arrangements through which requirements for individual and group participation in civic society are enacted² (Martin, 2004). More specifically, institutions are agents of “normalizing discourses” (Rhodes, 2001, p. 66)—ubiquitous, comprehensive, and often subtle phenomena which regulate power, interaction, and behaviour for the purpose of maintaining social order and control (ibid). Scholars suggest that institutionalization processes underscore the realization of political and social objectives, and facilitate the obligatory and often inhibiting practices inherent to the maintenance of normative belief systems (Martin, 2004). While these admittedly expansive definitions suggest that institutionalization is an abstraction that can be applied to almost all elements of human existence and exchange, this chapter will explore specific theorisations of institutionalization, as well as the development of its physical manifestation in the form of institutions or asylums in relation to historical attempts to deal with ‘deviant’ populations, that is, people who have historically been marginalized and fall outside strict social norms of appearance, behaviour, and ability.

This chapter is divided into three sections. First, institutionalization will be examined in regard to its relation with the “compulsive temporal and spatial arrangements of modernity” (Rhodes, 2001, p. 69), that is, as a constituent of contemporary society’s regulatory project (Corker & Shakespeare, 2002). Institutionalization will be examined as one feature in the nineteenth century quest towards objectified knowledge, “temporal and spatial” regulation, and categorization of difference. By drawing briefly on the work of critical theorists such as Kant and Weber, we shall see institutionalization as part of the movement towards the establishment of the

modern Western state, and will examine briefly its relationship to the ideological and political elements of the modern “state apparatus” (Park 1990, p.16). This section will also include a brief examination of Foucault’s work concerning the evolution and role of institutions. While institutionalization is often seen as an exertion of power from a prescribed set of rules and conditions (Tremain, 2005), Foucault’s work suggests that it is perhaps better understood as a response to an “omnipresent subtext” (Rhodes, 2001, p. 65), which dictates the parameters of the “regimentation and surveillance” (ibid) necessary for the preservation of the goals of modernity. Second, the relationship between the rise of institutions and economic forces will be examined. This discussion revolves primarily around two competing but interconnected notions as they appear in the literature: one, that the rise of institutions in the Victorian era can be adequately explained by Marxist and structural analyses; and two, that the establishment of institutions was a deliberate exercise of political will to control and categorize disruptive elements of the population. This discussion might best be described as a tension between notions of ‘inevitability’ and ‘intentionality’ regarding the development of institutionalization in the mid-late nineteenth and early twentieth centuries. As we shall see, neither explanation is independently sufficient, but the differing analytical starting points, as well as varying historic and geographic considerations, add to our understanding here. Finally, institutionalization will be examined as an embodied phenomenon, that is, how the notion of institutionalization is enacted in very real ways in people’s lives, particularly in regards to those consistently and historically positioned on the outskirts of cultural and social practice and discourse. This will include a brief exploration of the ‘asylum’, a prominent and tangible expression of the praxis of institutionalization.

At this point, it is important to clarify the temporal and qualitative context of this discussion. While this project deals specifically with the institutionalization of individuals in twentieth century Canada, as well as with the establishment of relevant institutions in the decades immediately prior, this chapter will necessarily draw from theorisations that span broader temporal and spatial periods. For example, Foucault's contribution to theorizations of the asylum draws exclusively from French history and institutionalization processes, yet offers insight into political and social impulses which are relevant to broader discussions concerning the development of institutions, including their development in nineteenth and twentieth century North America. Further, although this project deals with the institutionalization of people identified with intellectual disabilities, the theories from which this chapter draws deal with processes which affected people labelled 'deviant' for a number of different reasons—feeble-mindedness, madness, criminal behaviour, idleness, and poverty. The aim of this chapter, then, is not to draw only from theorists dealing with the specifics of the population and time period to which I have devoted this project, but to establish a broad theoretical foundation to assist in my general understanding of the nature of incarceration and the processes contributing to that phenomenon. Last, a clarification regarding some linguistic uses. While current understandings of the word 'asylum' generally suggest sites of incarceration for those deemed 'mad', and indeed, much of the literature works from this premise, I take liberty in this chapter to use the words 'asylum' and 'institution' interchangeably, as this allows for a breadth and depth of understanding. Likewise, for the purposes of this discussion, 'institutionalization' refers to the process by which individuals are deemed to fulfil the requirements for removal from the public sphere and placed in a regimented facility.

Institutionalization, modernity, and the state apparatus

The institutionalization practices with which this discussion is concerned, that is, the sequestering of marginalized individuals from mainstream physical and social locations, emerged in the nineteenth century, a post-Enlightenment era during which Kantian ideals of reason and order were regarded as steps towards the establishment of the successful modern state (Baynes, 2004). According to Simons (2002), Kant (1724-1804) asserts that the goal of modernity was to allow

the authority of intellectuals to provide universal standards of truth, morality, and taste in alliance with modern state rulers in a joint effort to establish modernity as a fundamentally ordered social and political system (p. 29).

While Kantian ideals have since been challenged, particularly by postmodernists (Simons, 2002) for their seeming unrelenting confidence in the potential for modern ideals to contribute to societal advancement, they have made a significant contribution to thinking which underscored the development of institutions. The ‘social order’ fundamental to Kantian thought helped shape modern systems of organization which eventually characterized nineteenth and twentieth century institutional practices. Indeed, the “classificatory and normalizing impulses” (Rhodes, 2001, p. 69) characteristic of institutionalization processes at the time were in close alignment with modernity’s obsession with the hierarchy of reason, at the top of which rested the autonomous and rational individual (Whitebrook, 2004). Further, the quest for measurable and positivist knowledge during this era (Gould, 1996) contributed to the meticulous study and analysis of ‘atypical’ populations and contributed to “metanarratives of deviance” (Corker & Shakespeare, 2002, p. 2), discourses which supported the categorization and sequestering of

‘undesirables’ away from the rest of the population. From this perspective, the institution might be seen as the realization of several modernist ideals, for it existed as both a site and a process through which the acquisition of knowledge, the classification of deviance, and the control of the non-independent and potentially disruptive subject could occur. In light of these reflections, Rhodes’ “omnipresent subtext” to which I referred earlier could be interpreted as the score, a ubiquitous agreement by which these processes were carried out.

In contrast to the optimistic and progressionist thinking which dominated late eighteenth century theories of modern advancement, Weber (1864-1920) offers a more guarded and, for our purposes, timely appraisal. Seemingly prophetic in his assessment of the consequences of modernity, Weber critiques bureaucratic formulations that limit and dehumanize human beings. Weber is critical of modernity’s attempts at “scientific-technological rationalism...the capacity to control the world through... modern science” (Ellis & Simons, 2002, p. 83). More specifically, Weber notes that rationalization, as embodied in modern institutional practices, discourages inter-reliance between social participants, and allows social understandings to become “decontextualized and impersonal” (Bernstein, 2004, p. 143). Further, Weber describes the fate of modern people to live in an “‘iron cage’ of bureaucratic domination” (Ellis & Simons, 2002, p. 83), a striking metaphor which, sadly, accurately describes the conditions under which many institutionalized individuals languished. Thus, Weber’s thinking, although not specifically concerned with the signification and placement of people of differing abilities in institutions, challenges the reasoning that justified its practice. In contrast to the predominantly broad appeal of institutionalization, which gained momentum during his lifetime, Weber observed that the bureaucratization which so heavily marked its practice could only lead to “loss and fragmentation” (ibid).

Foucault, although influential later in the twentieth century, maintains the thread of Weber's thinking regarding the limiting effects of scientific rationalism and bureaucratic mechanisms, and enriches analyses of the origins and practices of institutionalization. First, Foucault offers specific insight regarding practices which he refers to as "bio-power", processes by which bodies are "subsumed through an inexorable disciplinary regime" (McNay, 1994, p. 106) in order to fit within the limited definition of the normative contemporary subject. Foucault (1977) notes that at the end of the eighteenth century, "bio-power" was used to

... qualify, measure, appraise, and hierarchize... the juridical institution is increasingly incorporated into a continuum of apparatuses (medical administrative, and so on), whose functions are for the most part regulatory. A normalizing society is the historical outcome of a technology of power centred on life (p. 144).

Thus, the human body is rendered a subject of disciplinary power through measurement and categorization, and bears "the inscription of socio-cultural norms" (McLaren, 2002, p. 91). Accordingly, the abnormal body, bearing *not* the norms of "cultural inscription" (ibid, p. 92), but rather its expectations and lack thereof, becomes pre-disposed to placement, both physically and metaphorically, into liminal spaces—the prison, the asylum, the poorhouse—reserved specifically for the purpose of segregation. Bio-power as an administrative entity thus becomes the discursive justification for the placement of 'irregular' individuals.

Second, Foucault offers an analysis of power which contradicts the assumption, one which persists in contemporary debates, that power is singularly repressive in nature and bears "centralized external authority" (Tremain, 2005, p. 9). Rather, Foucault suggests that power consists of "guiding the possibilities of conduct and putting in order possible outcomes" (ibid, p.

8), implying that the exercise of contemporary power is more a subtle exercise of coercion than a series of confrontations. Further, the production of, and limits placed on, possibilities of conduct are concealed (Tremain, 2002), allowing the “naturalization and legitimation of the discursive formation in which they circulate” (ibid, p. 36). Power’s concealed yet pervasive nature is, in Foucauldian terms, the essence of surveillance, or the combined observation and repression of transgressive or disruptive societal elements. The pervasiveness of surveillance might best be described as a product of the “modern interpenetration of power and knowledge” (Rhodes, 2001, p. 65), and is an effective tool through which governing bodies can exert subtle yet exacting authority. Indeed, Foucault’s depiction of ultimate subjection—the prisoner who cannot escape the persistent view of the panopticon (Rhodes, 2001), Bentham’s archetypal model of the prison (Park, 1990)—is an example of the surveillance considered elemental to the disciplinary institutions established during this time period, and indeed, for several decades thereafter.

Thus, Foucault is helpful in that he interprets the mechanisms underlying the “regimentation and surveillance” (Rhodes, 2001, p. 65) characteristic of institutions which developed throughout the eighteenth, nineteenth, and early part of the twentieth centuries. He links these to “state apparatuses of control” (Park, 1990, p. 29) which did more to preserve and protect systems of regulation than to question their need and efficacy. Further, Foucault (1995) asserts that the power of regulation, combined with institutions³ as sites of knowledge containing intimate information about inmates and their lives, allows institutions to function as “apparatuses of knowledge” (p. 126), or instruments through which the state gains access to and exerts measures of social control. Last, Foucault introduces the notion that the rise of the asylum “was not merely a response to a pre-existing problem, but was the way in which the problem itself was

constituted” (Ingleby, 1983, p. 147), a point that will be pivotal in our examination of the development of institutions for people with intellectual challenges in North America.

However, Foucault also offers a historical interpretation that, while particular to eighteenth and nineteenth century France, introduces a line of thinking which will also prove salient in subsequent chapters. Foucault notes that in sovereign France, calls for institutionalization were made, in part, as a humanist cry for more humane and equitable treatment of people who had committed crimes against the monarchy. He suggests that the development of penal institutions stemmed initially and not indirectly from opposition to the nature and extent of punishment meted out via sovereign authority to individuals, criminal or otherwise, who threatened codes of social order and acceptability and challenged monarchical rule. Foucault (1977) notes that prior to the establishment of penal institutions, eighteenth century French disciplinary measures included severe spectacles of public executions and ceremonial chastisement, and were ways in which sovereign powers took measures to “re-establish justice [and] re-activate power” (p. 49), to “affirm the dissymmetry of forces” (p. 55) already in existence. Discipline, during this time period, was a corrective applied to rebellious behaviour and was a re-assertion of asymmetrical power distribution within the public sphere.

Accordingly, calls for more humanitarian treatment began to influence disciplinary measures which were considered essential to the maintenance of the social body. As Foucault (1977) notes, “at the beginning of the nineteenth century, the great spectacle of physical punishment disappeared, the tortured body was avoided, [and] the theatrical representation of pain was excluded from punishment” (p. 14). The form and nature of punishment began to shift from the bloody spectacle to curative or corrective measures (p. 10)—“not to punish less, but to punish better” (p. 82), with the intention of returning the deviant individual back into productive

society, to “reinsert them morally and materially into the strict model of the economy” (p. 124). Thus, Foucault makes the essential point that although the call for more humane forms of discipline, including the use of institutions, seemed to originate from those intent on reforming barbaric methods of dealing with deviance, it remained “a calculated economy of the power to punish... a correlative technique of power” (p. 101)—in other words, a state-sanctioned method to suppress deviance and support social productivity. Although the time period and conditions under which institutionalization relevant to this study differ significantly from those to which Foucault refers, the reformist intentions which underlie their development originate from similar, and not necessarily unjust impulses. In the years of concern here, that is, the latter part of the nineteenth and the early part of the twentieth centuries, the primary driving force behind institutionalization relied on the conviction that to house the mentally and intellectually ‘unfit’ in state-run establishments was the most humane and reasonable response to concerns about their welfare, a line of thinking remarkably parallel to that which Foucault explicates. Thus, a pattern emerges which suggests that institutionalization processes are intimately connected to discourses of reform and humane treatment, discourses which have emerged at various points in history and for different reasons, and have profoundly affected decisions made on behalf of those most vulnerable to their outcome. This point will be returned to at various points, including the next section, which is concerned with the relationship between the rise of institutions and economic forces.

Inevitable / intentional: Institutionalization and economic forces

Debate concerning economic and socio-political forces which contributed to the development of institutions can be distilled into two primary points of argument. One group of authors, Scull the most notable among them, asserts that institutionalization was an inevitable

process, a development “powerfully constrained by structural factors...intimately linked to a whole series of historically specific and closely interrelated [social] changes” (Scull, 1983, p. 126). This is countered by other, perhaps less forgiving theorists, including Rothman, who claim that institutionalization, despite the rhetoric of reform, was an intentional series of policies made in response to a “felt need for order and discipline...in a society deeply apprehensive about the prospect of disorder” (Rothman, 1971, p. xxxiv). This section will address each of these theoretical positions in turn, revealing that a comprehensive understanding of the forces underlying the development of institutions depends on contributions from both.

Before proceeding, a point of clarification is needed. The two principal theorists from whom this discussion draws (Scull and Rothman) work from two different geographic and historical perspectives. Scull’s contributions stem from a historical materialist analysis which focuses on institutional development in Victorian England. Accordingly, his analysis is relevant to ideas fundamental to the social model of disability. Rothman, on the other hand, provides an analysis of the development of the asylum in the Jacksonian era of the United States, a time marked by the contribution of the ‘common man’ in an effort to distance the new American republic from the template of monarchial England. While it might be tempting to state that each author thoroughly encapsulates the asylum movement on each continent, it is probably more accurate to recognize the importance of each theorist’s contributions to the other, and to our understanding here.

The first group of theorists links the development of the modern asylum to shifts in economic and labour forces during the Victorian era. In the mid-to-late 1800s, rural, agrarian-based society moved rapidly to become urban-centred and industrialized, and capitalism gained momentum as the primary framework of production (Finkelstein, 1980). As Oliver (1990) and

other disability theorists have pointed out, this was a pivotal moment in the social position and perceived contributory possibilities for people with disabilities. Indeed, much social model theorizing stems from a Marxist critique of capitalism which points out its exploitative nature, particularly for those upon whose work the capitalist system depends. Meaningful possibilities for people with disabilities within capitalism only diminished as its impetus and influence grew:

... there are strong economic reasons for the exclusion of disabled people and it is the embodiment of these social and economic relations under capitalism which has led directly to the exclusion of disabled people in capitalist societies (Oliver, 1990, p. 21).

This shift in economic and political priorities during an era of increasing industrialization, that is, “the transition from the old paternalist social order of a fully capitalist system, provided a direct source of bourgeois dissatisfaction with the traditional, non-institutional response to the indigent” (Scull, 1979, p. 34). This phenomenon, along with an increasing emphasis on the scientific classification of individuals falling outside functional norms (Davis, 2010), and “the importance of distinguishing the able-bodied from the non-able-bodied poor” (Scull, 1979, p. 37), resulted in a societal vacuum in regards to the role and position of people with disabilities. This combination of factors allowed the reformists’ call for the development of centralized, state-run locations of care for those considered less intellectually capable to begin to have some impact (Oliver, 1990).

Moreover, Scull (1983) suggests that there were virtually no plausible alternative responses to people considered mad or disabled during the Victorian era (p. 131). He states that to introduce support which “approximated a modern social welfare system” (ibid) at this time

would have proven disastrous to the developing dependence on market forces, and that the predominant “ideological hegemony of classical liberalism...rendered the very notion of social protectionism anathema” (ibid). That is, if people with disabilities and their families were to receive financial or goods-based support in order to maintain a life in the community, this would counter the modernist doctrine of personal self-interest and responsibility (ibid), and would allow an inequitable system to develop in which those receiving support would inevitably gain access to a lifestyle previously out of reach, while “their same brethren [would be] subjected to a Poor Law based on the principle of less eligibility” (p. 131). Besides its apparent unfairness, Scull argues, such a system would also have been virtually unworkable from an administrative perspective (ibid). Thus, Scull suggests that the “shift to the asylum” (p. 130) was not one option of many, but was, rather an inevitable process, “deeply embedded in the structures of the nineteenth century” (ibid), that those spearheading their development “could have acted otherwise only with extreme difficulty” (p. 126), and that any suggestion of communitarian support would have been disagreeable to those with political power.

These arguments must be tempered, however, by the acknowledgement of the a-priori existence of the precursors to Europe’s modern social welfare systems, for example, the Poor Laws in England (Slack, 1990), and the compulsory social insurance measures brought in during the Bismarckian era in late-nineteenth century Germany (Bonoli, 1997). While these early social policies did not necessarily embrace current notions of egalitarianism (Esping-Andersen, 1995, p. 1)—that is, the Bismarckian tradition was marked by “earnings-related benefits...conditional upon satisfactory contribution records” (Bonoli, p. 357), and the Poor Laws were clearly originally intended for “impotent persons” (Slack, p. 6)—it must be noted that some form of social assistance was available through legal contract in parts of Europe in the late nineteenth

century (Rose, 1971). However, as Scull (1983) points out, these precursors to what we now know as social welfare systems did not prevent what he has termed the “embedded” (p. 130) and inevitable move to the asylum. He (1979) notes that the “functional requirements of a market system... promoted a ... crucial distinction between two broad classes of the indigent” (p. 40), that is, a distinction between those who possessed the physical and intellectual capacity that participation in the rigorous market system required, and those who did not. Thus, “making separate institutional provision for a troublesome group” (ibid, p. 41) made sense, a move that ensured that “a source of potential danger... could be removed to a place where such people could no longer pose a threat to the social order” (ibid).

Scull’s work regarding the capitalist underpinnings of the development of the asylum has been supported by other scholars. Ignatieff (1983), for example, suggests that the reproduction of capitalist society depends upon the “constant interposition of state... controls and repression” (p. 96), and that “penal sanction is essential to the reproduction of the unequal and exploitative social relations of the capitalist system” (ibid). That is, the production deemed essential to capitalism is dependent upon unequal relations and centralized control, both features of a system which includes institutionalization as one way to deal with members of the population considered less productive. Further, Thompson (as cited in Cohen & Scull, 1983) notes that despite the limitations of a materialist analysis, “ideological structures” have a significant impact on patterns of social control (p.4); in other words, the fundamental systems which support capitalism have a bearing on the nature and extent of control over particular groups of people within the population.

Moreover, the relationship between Victorian notions of productivity and the burgeoning market economy had a significant bearing on the purpose and design of asylums in

the latter half of the nineteenth century. While this will be discussed in greater detail in subsequent chapters that deal with the development of institutions in North America, particularly in regards to people with intellectual disabilities, it is important to note at this point the importance that Victorian society placed on hard work, both as a means through which one contributed to society, and as a curative measure. Institutions were developed not only as places to house the poor, the mad, the disabled, and the indigent, but as a controlled site through which institutionalized individuals contributed their labour, designed and sanctioned by the state, for several purposes: to meet the insatiable needs of a growing capitalist society, to maintain the microcosm of the institution itself, and to contribute to the moral and physical ‘rehabilitation’ of its residents (Radford & Park, 1993a; Reaume, 2000; Trent, 1994).

While the explanations above assist in our understanding of the relationship between economic forces and the rise of the asylum, there is need to address this historical movement from a broader perspective. To this end, Rothman makes a significant contribution. Rothman (1983) contends that to rely solely on economic explanations “leaves too much out of the story” (p. 115), and his principal argument is that the establishment of the asylum in nineteenth century America was driven primarily by a ubiquitous fear of social disorder and moral “dissolution” (1971, p. xxxix) in the new republic. Rothman claims that in post-colonial America, “traditional mechanisms of social control were obsolete” (p. 58), and that the weakened authority of the family and community, as well as the “aggressive demands of a submerged labouring class” (p. xxxix), gave rise to a generalized anxiety concerning the establishment of order and stability. The social and geographic mobility which emerged in the Jacksonian era did not inspire confidence in the communal ability to maintain order. Thus, according to Rothman, the asylum was the politicized and intentional response to a generalized fear about potentially disruptive

elements, and that “to comprehend and control abnormal behaviour [was] the first step in establishing a new system for stabilizing the community, for binding citizens together” (p. 58).

Rothman’s analysis also points to the socially constructed nature of disability as evidenced by the development of the asylum. He (1980) notes that the asylum, in addition to being a tool of social control, became a site of justification for the categorization and confinement of people of varying capacities and backgrounds (p. 23). As noted in the above section addressing Foucault, the asylum was not only a place of incarceration, but contributed to the social construction of the identifications requiring incarceration in the first place. That is, the asylum became part of the self-sustaining regulatory machine which provides both the classificatory measures needed to create the groups of people seen as needing institutionalization, and the final site to which they are relegated. In this way, the asylum fulfils the disciplinary mechanisms which Foucault explicates. Thus, the asylum occupies more than ‘site’ in the historical-social landscape, but rather, is simultaneously both agent and product in the social construction of disability.

Moreover, Rothman (1980, 1971) explores the reasons underlying asylums’ longevity even after their rehabilitative and organizational promise had transpired. He notes that North American institutions lived on “long after the dream turned into a nightmare” (1971, p. xliii), and that the reliance on institutional care continued to grow (p. xxxv) despite an increasing awareness that the asylum offered, for all intents and purposes, nothing in the way of the moral, physical, or spiritual recovery that the original reformists had intended. In the strange manner in which self-justificatory mechanisms perpetuate themselves, Rothman notes that the crowded conditions “justified the [asylums’] continued existence” (1980, p. 374), and that their endurance was the result of decisions of convenience, in which “institutional survival, not patient welfare,

[became] the ultimate consideration” (p. 375). Accordingly, superintendants’ claims that they were playing an essential role in the care of “social waste” (ibid) did much to cover up any attempt to question the convenient lowering of the threshold of tolerance for standards of behaviour deemed essential to community living (1971, p. xliii). Rothman’s analysis thus suggests that an examination of the longevity of asylums must go beyond the reformists’ rehabilitative rhetoric, as ill-informed as we now know that to be, and must include an examination of the ubiquitous fear and abjection which motivated incarceration processes. Indeed, Rothman points out that institutions embraced an “unflagging readiness to keep the deviant out of sight and out of mind” (p. xxxv), a mandate which had an extensive and unfortunate reach into several marginalized populations.

A final word regarding Rothman’s assessment of the development of institutions is called for. Rothman’s contention regarding the intentionality of the establishment and propagation of the asylum suggests that there can exist in equal measure a directed response to alternative and more humane models of care. In his words: “we need not remain trapped in inherited answers” (1971, p. 295). Indeed, in the recognition of the mistakes made in the assessment of the care needed for particular populations, Rothman’s assessment is hopeful, and suggests that the premise of inevitability upon which Scull and other materialists rely, while essential to a thorough understanding of the development of the asylum, can be broadened to include an examination of other enduring and underlying factors.

Institutionalization as an embodied phenomenon

Recent scholarship, particularly that attentive to gender, has drawn notice to the embodied nature of institutionalization processes (Martin, 2004; Rhodes, 2001; Shildrick, 2009, 2002). By ‘embodied’, I refer specifically to the impact of discursive practices, particularly those

which constitute institutionalization, on the materiality of the body (Shildrick, 2002, p. 10), as well as their reversal—the role that discourse concerning divergent bodies has on the establishment of exclusionary practices. As Martin (2004) notes: “the ‘material’ body is key... the practices and interactions of ‘real’ people with bodies that talk and act [*sic*] constitute social institutions” (p. 1251). Grosz (1994) reminds us that the body is a repository for cultural praxis, “a site of social, political, cultural, and geographical inscriptions” (p. 23), and is thus both the vehicle through which institutionalized disciplinary practices are enacted, and the justification for their implementation. This section will explore the nature and extent of the institution as an embodied phenomenon: first, by examining the theoretical underpinnings of the historical impulse to isolate ‘messy’ elements of the social body, and second, the impact this has on the lived materiality of the body.

Evidence of the felt need to contain individuals considered disturbing, or, in more troubling terms, repulsive to the social fabric, extends far back into the historical record. While the theoretical frameworks discussed above emphasize economic and materialist perspectives, scholars also stress the need to study the relationship between institutionalization and the suppression of chaotic and disruptive elements of the human condition (Goffman, 1961; Scull, 1979). Scholars from other disciplines, notably anthropology, contribute to this analysis, which deals with the human tendency to shrink away from that which is unpredictable and messy, a perspective that has historically justified the institutionalization of people with disabilities (Park, 1990; Radford & Park, 1993a). Douglas (1966), for example, suggests that rituals concerning communal or individual elimination of pollution or “matter out of place” (James, as cited in Douglas, p. 35) are long-standing historical practices, and are manifested literally and symbolically in the pushing aside of undesirables into marginal or liminal spaces. While Douglas

does not deal specifically with rituals of exclusion concerning people with disabilities, she explores the transhistorical impulse, often deeply interwoven with the collective desire to achieve holiness or completeness, to abolish ambiguity or anomaly. That is, the well-being of the sacred or political body is dependent on the “integrity, unity, and purity of the physical body” (p. 124) and on the steps taken to classify, banish, and indeed sometimes eliminate that which threatens to pollute or confuse agreed-upon requisites of belonging. Further, the link between such agreements and the sacred provides a sense of infallibility: the abolition of ambiguity is approved through a pre-ordained agreement with a corresponding deity.

Kristeva (1982) furthers Douglas’ thread concerning the banishment of the anomalous subject, that which “disturbs identity, system, order” (p. 4). Kristeva re-iterates the historic inclination to name and contend with “borderline subjects” (p. 7) who present a “threatening otherness” (p. 17) to the common good. Prohibitions against ambiguity or difference are established to instill order (p. 104), a point which echoes some of Rothman’s arguments discussed earlier. However, Kristeva diverges from other theorists in her use of psychoanalytic theory. She suggests that the abjection of the other is merely a reflection of the abjection of self, and that its banishment, more than an external riddance, is an indication of the individual need to rid oneself of the ‘lack’ which one most fears in oneself⁴. Thus, Kristeva’s question—“what social, subjective, and socio-subjectively interacting need does it [abjection] fulfil?” (p. 92)—suggests that theories of institutionalization must go beyond economic and political mechanisms, and interrogate psychic and emotive inclinations.

Also from the anthropological canon, Rhodes (2001) further suggests processes underlying the segregation of individuals deemed disruptive to the social body. Writing about the exclusionary practices of modern-day prisons, Rhodes (2001) notes that incarceration “relieves

us of the responsibility of seriously engaging” (p. 67) with problematic populations. That is, institutionalization provides the rules of engagement—or indeed, of non-engagement—for dealing with those for whom there seems to be no easy long-term solution. While such ‘solutions’ were initially framed as methods of care through which people with intellectual disabilities might be ‘rehabilitated’ and returned, whole and fit, to a meaningful place in society (Rothman, 1971; Trent, 1994), these gradually shifted, through the rhetoric of public safety, to an ideology concerned with the establishment of clear boundaries between people living outside of institutions, and the threat contained within (Rhodes, 2001). This point will be taken up in greater detail in subsequent chapters, but Rhodes’ point is well taken here: incarceration, in its various guises, permits a lack of commitment to the needs of ‘problematic’ groups of people, and serves instead to assuage public concern regarding their care, and to maintain clear boundaries against incarcerated individuals’ potential risk to public security.

While the paragraphs above outline theoretical frameworks underpinning the embodied nature of institutionalization, other authors provide first-hand accounts of life inside institutional walls. Hubert (2000b), for example, articulates some of the more harrowing implications of long-term institutionalization on the lives of people with intellectual disabilities. She notes that the social implication of long-term institutionalization goes beyond dismissal of the ‘other’, and facilitates a profound “desocialization and dehumanization” (p. 200) of the incarcerated, a tacit yet unanimous “acquiescence...to the men’s [sic] social invisibility” (p. 201). Hubert suggests that the “legacy of separateness and stigma” (p. 206) with which institutionalized individuals must continuously bear, as well as the often horrific conditions of the institutional setting, removes them from the normal “patterning of society” (Douglas, cited in Hubert, p. 197) through which we become accepted members of the broader community.

Hubert's first-hand account of observations that she made while spending time in a locked ward of an institution for people with intellectual disabilities echoes the influential work done by Goffman in the 1960s. Goffman's (1961) analysis of confinement practices in the United States in the mid-twentieth century provides three essential insights. First, he notes the systemic and structural functionalist nature of institutions wherein each member of the mechanism, both patient and staff, plays a particular role in its maintenance. This allows for the professional 'management' of people considered deficient, and mirrors the bureaucratic system of power and subordination existing outside asylum walls (p. 104). Goffman points out the symbiotic relationship between the asylum and the professionalization of care, such that entire professions are dependent on, and affirmed by, the maintenance of the institution, a point taken up vehemently by other scholars (see, for example, Trent, 1994). Second, Goffman gives a detailed account of inmates' efforts to create some sort of meaningful way of life, often under unbearable and inhumane conditions.

When existence is cut to the bone, we can learn what people do to flesh out their lives. Staches, means of transportation, free places, territories, supplies for economic and social exchange—these apparently are some of the minimal requirements for building up a life (p. 305).

Goffman speaks of residents experiencing "abandonment, disloyalty, and embitterment" (p. 133), to the point of being "stripped of almost everything" (p. 140)—a metaphor which returns us to the embodied manifestation of institutionalization practices. The depravity of which Goffman speaks is mindful of Grosz' "social, political, cultural, and geographical inscriptions" that the body bears when subjected to the regime of the institution.

Last, Goffman notes the irony inherent to institutionalization practices—the more ‘deviant’ the individual, the greater the requirement for control; one’s behaviour justifies the need to extinguish it via the confines of the asylum. That is, far from being seen as expressions of self-autonomy, attempts to “build up a life” (p. 305) are deemed resistant and confrontational by the authorities, justifying the institutions’ existence. One of the profound sadnesses in the history of the asylum is that institutionalization always “outmanoeuvres the patient, tending to rob him of the common expressions through which people hold off the embrace of organizations” (p. 306). In other words, the patient can never win. The desire to create a home is interpreted as rule-breaking, and is squelched at every opportunity.

Conclusion

This chapter has presented an overview of some of the theoretical perspectives on institutions, or asylums, and processes of institutionalization. While this summary does not address solely the historical and geographic period to which this project is devoted, it provides a foundation from which an understanding of institutionalization practices relevant to this project might be initiated. At this point, the discussion will turn to the development of institutions more specifically designated for people deemed ‘intellectually inferior’, and in particular, their rise to prominence in Ontario.

Chapter Two: Historical and contextual factors

Introduction

This chapter serves as a link between the theorizations of institutionalization discussed in the previous chapter and the rise of institutions for the ‘feeble-minded’ in North America, which is addressed in Chapter Three. In this chapter, three historical movements that have contributed significantly to this phenomenon will be examined. The first concerns the role of charitable impulses in the development of the institutionalization of people with disabilities, including interventions by church and government. The second concerns the establishment of the notion of the ‘average man’ in the nineteenth century, a development which, with the support of the burgeoning field of statistics, facilitated the socio-political construction of the ‘abnormal’. This, in turn, led to the establishment of segregated geographic and political sites for the ‘feebleminded’, considered essential within a model of custodial care and control. Third, I will address other phenomena which contributed to the establishment of institutions in North America, such as the prominence of eugenic thinking and policy at the turn of the twentieth century, and the related implementation of restrictive immigration policies.

Charitable concerns and institutionalization in the modern era

Charitable motivations have played a significant, and, in the disability studies community, contentious role in the development of institutionalized care for people with disabilities (Barnes, 1997; Barnes et al, 1999; Oliver, 1996; Shakespeare, 2006; Trent, 1994). Historically, these intentions have frequently been framed within reformist rhetoric which suggests a sense of constructive movement in the care of people who occupy spaces on the margins of society. Scull (1979) points out that some of the major shifts in institutionalized care which occurred in the eighteenth and nineteenth centuries—that is, a significant increase in state

involvement in the care of marginalized populations; the “differentiation between different sorts of deviance” (p. 17); and the trend to increasingly segregate the deviant from the surrounding community (ibid)—were frequently couched as reformist and well-intentioned, reflecting the ubiquitous and influential progressionist interpretation of history during that era (p. 14). These trends, according to Scull, might be better understood rather as a “wider transformation of the mechanisms for the social control of problem populations” (pp. 17 / 18), less influenced by the well-intentioned motivations of various professional and religious groups than by the requirements of the ever-strengthening capitalist economy. However, despite the obvious influence of capitalist development on the rise of institutionalization as a method of containing deviant populations, it was frequently justified as a charitable and well-meaning response (Trent, 1994). The varying meanings underlying the justification for institutionalization suggest that some interrogation of the influence of charitable incentives on the development of institutions is warranted.

Known charitable responses¹ towards people with disabilities stem originally and predominantly from religious communities, which have historically framed the care of people with disabilities as an obligatory component of spiritual observance (Stiker, 1999). Indeed, connections between charity and church history are well documented (Covey, 2005; Eiesland, 1998; Hall, 1983; Metzler, 2006), and Christianity, throughout its history, has consistently situated the response to disability within a moral and ethical framework (Jonsen, 2000; Porter, 1997). Stiker (1999) in particular notes the simultaneous development of the notion of the responsibility to perform works of charity with the rise of institutional models of care in seventeenth and eighteenth century Europe. According to Stiker, earlier, medieval responses to anomaly were “neither revulsion, nor terror, nor treatment” (p. 68), but were, rather, an

acknowledgment of the “infinite diversity of God’s creation” (ibid, p. 68), an expected “part of the great human lot of misery” (ibid, p. 79). He notes, however, that organized responses to disability in the form of charity became more pronounced from the sixteenth century onwards, manifested primarily through the establishment of medical and educational institutions, precursors to present-day hospitals, often under the auspices of religious orders. These were frequently regarded as instruments of “entry to the common cultural and social heritage of their fellow citizens” (ibid, p. 107), a heritage from which many people with disabilities might have otherwise been excluded. Indeed, these early hospitals, which were literally defined as places of welcome for people considered poor and indigent, carry historical relevance in that they established the tradition of an organized and ostensibly necessary response to the needs of people on the margins of society, many under the patronage of religious organizations which carried a significant amount of political and social influence. A notable example of this kind of response is found in the work of St. Vincent de Paul (1581-1660), who established a network of charitable almshouses in seventeenth century France with the intention of caring for people who were poor, ill, or elderly, all embedded within a strong foundation of religious instruction. As Stiker notes, however, de Paul’s objective was not only to provide relief to indigent individuals, but to “Christianize” the poor (ibid, p. 98), suggesting that there were personal and perhaps political motivations underscoring de Paul’s work.

The work of Eduard Seguin (1812-1880), a French expatriate who established several training and educative institutions for ‘idiots’ in the United States, is another example of a project which began with honourable intentions, but whose end result was less than favourable for people with intellectual disabilities. Seguin had hoped, through a specific pedagogy, to provide skilled instruction and moral treatment for the ‘feeble-minded’ such that they might

return to home and community and provide a valuable contribution. However, as industrialization increased in the United States after the Civil War, and the presence of the ‘feeble-minded’ became “a hindrance to the social and productive order” (Trent, 1994, p. 59), the pedagogical nature of Seguin’s institutions shifted, and echoed the movement, happening elsewhere throughout North America (Simmons, 1982) to a custodial, as opposed to rehabilitative, type of institutionalized care. This shift in intention and focus, from a charitable model to one within which oppressive measures became de rigueur, is due in part to the eviscerative effects of long-term institutionalization on both inmates and staff (Goffman, 1961), and the increasing emphasis on maintaining the roles of professionals who were dependent on an institutional model of care (Trent, 1994).

The work of these two men exemplifies the tension underscoring current discussions concerned with charitable responses. A broad historical perspective suggests that, in many instances, these services were the lone social response which concerned themselves with the needs of people with disabilities. While disability scholars have suggested that prior to industrialization people with disabilities often carried productive and meaningful roles in communal and agrarian settings (Finkelstein, 1980; Oliver, 1990), historians from outside the field have noted that the situation for many people with disabilities prior to an institutional response was equally as dire outside the containment of institutions as within (Scull, 1983). While our current understanding confirms that the use of large-scale institutions was fraught with difficulties and human rights abuses, it remains imperative to do the genealogical work needed to understand the motivations and social conditions underlying their development. This kind of excavation is particularly relevant when opposing interpretations exist, such as the merits and drawbacks of a charitable approach. That institutions culminated in horrible sites of containment

and oppression does not belie the fact that for many people with influence at the time, they were considered the most humane way to support marginalized populations.

In general, however, scholars agree that we must not lose sight of the fact that institutions laid the groundwork for less favourable conditions, far from their original charitable intentions:

These institutions, however fruitful they were... remained institutions. They are the forerunners in many respects of what would become in our century the almost single formula for persons afflicted with malformations, inherent or acquired (Stiker, 1999, p. 107).

Critics suggest that even in the earliest days of their development, institutions contributed more to the management and surveillance of people with disabilities than with their wellbeing. That is, even though framed within the context of moral responsibility and generosity, these institutions played an increasing role in the maintenance of social order over ‘deviant’ and potentially unproductive citizens (Borsay, 2002). Institutional hegemony over large assemblies of ‘unusual’ persons, despite their charitable intentions, contributed to medicine’s burgeoning “supervisory aspirations” (ibid, p. 111), and facilitated the Christianization of large groups of people. Thus, institutions became tools through which the scientific and evangelical goals of particular groups could be realized; their framing as a worthy response to a profound need facilitated their broad acceptance. This notion is supported by Foucault (1965), who, in his work on the Great Confinement in seventeenth century France (pp. 44-77) notes that institutions for the mad and the disabled, many of which were run by religious orders, were “vectors of both assistance and repression[;] these hospitals were intended not only to assist the poor but also for imprisonment...

the gesture of confinement was ...equally complex, and it... had social, political, religious, economic and moral meanings” (p. 51 / 52).

It is these underlying and complex moral meanings which have offered so much contention within critical disability scholarship. Tension between the potential benefits and repressive elements of charitable responses towards people with disabilities has remained imperative in the field. The majority of social modellists (see, for example, Barnes, 1997; Barnes et al, 1999; and Oliver, 1996) have been consistently critical of charities in analyses of historical responses to people with disabilities because of their tendency to frame disability as a passive condition requiring assistance, which does little to facilitate people’s autonomy or independence, or to foster realistic understandings of the varying and diverse conditions of disabled people’s lives. Garland Thomson (2001) notes that the images put forward by charitable organizations achieve their intentions by situating disability as the “manifestation of suffering” (p. 341), in a position hierarchically lower than the non-disabled viewer / giver, and through these mechanisms, serve the propagation of narrow capitalist narratives of disability, a tool used to “evoke pity, inspiration, and frequent contributions” (ibid). Indeed, within current socio-political arrangements, the one-sided nature of charity does not resonate well with models which support people with disabilities to live lives of meaning and self-sufficiency.²

Further, other scholars suggest that Foucault’s suggestion of “complex meanings” underlying the relationship between charity and institutionalization include a little-theorized dynamic between paradigms of normativity and the pervasive fear of difference (Wilton, 1998). That is, charity, and the kind of giving that it generally asks of people, can be seen as a culturally-accepted securing of one’s distinction from those considered deviant. Through the auspices of charity, one establishes one’s power in a relationship, as it is specifically defined by

corporeal or intellectual variances; one secures one's identity as someone who participates in the abolition of unwanted conditions; and one secures one's distance from the deviant by ensuring that any kind of meaningful relationship is prevented by the existence of one based solely on the charitable dynamic. For example, Longmore (2010) notes that current practices of charitable giving, embedded within consumer capitalist society, encourage the unhelpful depiction of people with disabilities as incomplete entities who possess the potential for miraculous cure, which can be secured through financial donations from the public. Further, charitable frameworks secure the able-bodied population's perpetual cultural and moral approval by encouraging monetary participation in the erasure of disability (Kuppers, 2007; Longmore, 2010; McRuer, 2006), and protects the able-bodied's (false) perception that this ensures distance from embodied difference (Wilton, 1998). Moreover, this practice has historically been strengthened by its association with religious mores and values (Brooks, 2003; Rose, 1997), a framing that provides justification for what is essentially a heavily mediated and lopsided response.

In sum, charitable impulses have played a significant role in the development of institutions, particularly when examined within the religious and moral understandings at play during key periods of their development. This thread, often depicted as a reformist and progressive ideology, has remained firmly in place throughout the evolution of institutions, despite various guises and locations, and will be discussed further in the examination of the development of institutions in North America.

Genetic determinism, intelligence testing, and the average man

The use of institutionalization as a strategy to deal with people considered 'feeble-minded' in both Europe and North America coincided with a burgeoning interest in the fields of genetic determinism, inherited intelligence, and increasingly rigorous definitions of normality.

The nineteenth century notion of a measurable, reified intellect, and a ubiquitous belief in the extent to which people of ‘lower’ aptitude were a hindrance to the establishment of a productive body politic (McLaren, 1990; Trent, 1994) are central to our understanding of the eventual institutionalization of people with intellectual disabilities in North America.

A fundamental piece of this historical understanding is the notion of the ‘norm’. Disability scholar Lennard Davis (2010) locates the construction of disability within the nineteenth century socio-political shift away from the romanticized notion of the ‘ideal’, to that of the ‘norm’, or average. Prior to the nineteenth century, Davis claims, artistic and literary works represented corporeal and intellectual ‘ideals’ to which no one person could aspire. The ideal was not a tangible existence within which one could realistically locate oneself; accordingly, its corollary, the norm or the average, also did not (as yet) have a firm footing in socio-political discourse. The lexical emergence of the norm, rather, occurred in the mid-nineteenth century, and it coincided with the rise of statistics, or the use of “social numbers” (Porter, 1986, p. 18) as a kind of “political arithmetic... [for the] promotion of sound, well-informed state policy” (ibid). Information originally intended to describe the “wealth and strength of the state” (ibid, p. 19) expanded to include the tracking of health and disease as a way to maintain surveillance and to inform administrative decisions. It was via the recognition of statistics’ contribution as a bone fide and relevant discipline in the establishment of a strong nation state that the notion of the ‘norm’ was firmly recognised. Adolphe Quetelet (1796-1847), a French statistician, was instrumental in this adaptation and was a key proponent of the idea of the “normal as an imperative” (Davis, 2010, p. 5). Quetelet advanced the notion of the abstract and average “*homme moyen*” (ibid), and by extension “*les classes moyens*” (ibid), which served both to extol the virtues of a middle class and bourgeoisie existence, and to accentuate the

demarcation of those falling outside the corporeal, intellectual, and productive average. This formal recognition of an ‘average’ and its resultant deviations, Davis suggests, is vital to disability scholarship, as it provides both historical context and semantic depth to the notion of the construction of difference, deviance, and disability.

The construction of the norm became increasingly appended and narrowed throughout the late nineteenth and early twentieth centuries (Trent, 1994), consolidating the high socio-cultural regard for “prevailing standards of physical and / or mental normalcy” (Strong-Boag, 2007, p. 414). While Quetelet focussed on the “hegemony of the middle” (Davis, 2010, p.6), the epistemological thread picked up by late nineteenth century statisticians began to stress the importance of ranking individual and group characteristics. That is, while a true ‘normal’ distribution suggests that existences at either end are extreme and hence avoidable, social scientists at the time determined that a ranked system of desirable traits might be more productive. This ranking took many forms. Galton (1822-1911), for example, a British statistician who devoted his career to the advancement of eugenic thought, developed what he called an ‘ogive’, an offshoot of the normal distribution curve, which ranks ‘desired’ traits figuratively ‘higher’ than average qualities. Thus, for example, while tallness would theoretically fall within the ‘extreme’ end of a normal distribution curve, Galton’s new methodology allowed that tallness would fall at the high end of the ‘ogive’, mirroring the high regard for tallness prevalent in Victorian England. This arbitrariness of the qualifiers for desirable traits spilled over into all areas of statistical measurement of the population, including intellect, and ultimately influenced future decisions regarding the care and regulation of people with intellectual disabilities.

Further examples of the progression of the ubiquitous reach of segregative assessment and categorization are found in the realm of intelligence testing. In the United States and Canada between 1900 and 1930, the increasing use and indeed, strategic manipulation of standardized testing by professional and academic elites played a significant role in determining the enduring economic, geographic, and social boundaries within which people with disabilities have been appropriated (Gould, 1996). For example, Binet's (1857-1911) intelligence tests³, which he initially developed at the request of the French government to assist in the identification of students who required extra assistance in school, were seconded in the decades leading up to the second World War by other scientists—Goddard, Terman, and Yerkes in particular (Gould, 1996)—for the specific purpose of ranking individuals according to intellectual and functional capacity. Goddard (1866-1957) in particular altered the original intentions of Binet's tests: he advocated for a 'reified' understanding of intelligence (that is, intelligence as a non-flexible, innate and measurable entity), promoted the tests' usage in American schools and work places, and elaborated on earlier taxonomies of intelligence by adding the category 'moron' or 'high-grade defective' to the already-existing classifications 'idiot' and 'imbecile'. Goddard is probably most infamous, however, for his now disreputable research regarding the 'Kallikak' family, in which he determined that feeble-mindedness is indeed passed on to subsequent generations through faulty genetic inheritance⁴. Goddard's work, although now ridiculed for its complete lack of scientific basis or sound methodology, had the unfortunate effect of initiating a discourse of justification for the classification and sequestering of people with lower intellectual capacity. Goddard warned of the impending "menace of the feeble-minded" (cited in Trent, 1997, p. 131) to the advancement of modern society. Along with dire intimations of the looming

threat of increased immigration from southern and eastern European countries, Goddard's admonitions carried significant influence (Trent, 1994).

While it is beyond the limits of this chapter to discuss in detail the work of American psychologists and educators Terman (1877-1956) and Yerkes (1876-1956), they are worth mentioning here because of their influence in both the revision and dissemination of Binet's original scale, and its adaptation to military purposes, respectively. Terman adapted and standardized the Binet test, renaming it the Stanford-Binet in 1916; it has since become the "paradigm for virtually all the written versions" (Gould, 1996, p. 207) that have followed⁵. Yerkes' work was influential both as a screening tool within the military, his original intention, and because it demonstrated the far-reaching possibilities for ranking, streaming, and mass testing (ibid, p. 225) within educational settings.⁶

These examples of the various uses of intelligence testing in the early decades of the twentieth century in the United States are relevant to the contextualization of institutionalization for a few reasons. First, the arbitrary nature of the tests, which relied on a "hereditarian theory of unitary intelligence" (Gould, 1996, p. 47), wherein factors such as social conditions and language were not considered, is indicative of the constructed nature of intelligence testing and indeed the socio-political construction of intellect in general (ibid). These constructed, restrictive definitions of intellectual capacity which dominated educational and social circles at the time served well the pervasive discourse of progress and the felt need to categorize and contain those who might undermine the progressive project. Second, the arbitrary nature of intellectual assessment ensured an expanding pool of non-desirables. While Binet's original intention for the test was that it be used as an educational tool—to "help and improve, not to label in order to limit" (Gould, p. 182)—the perversions which ensued ensured, contrarily, that the

‘feeble-minded’ were identified with increasing regularity and scope (McLaren, 1990). Indeed, scholars have noted the historical trend of rapid increases in ‘identified’ populations whenever testing standards shift or normative thresholds of capability and behaviour are altered, a trend with particular credence during times of social or political unrest (Allen, 1997; Davis, 1997; Gould, 1996; McLaren, 1990; Strong-Boag; Trent, 1994).⁷ Such demographic shifts have historically been used to justify the existence of segregated settings, including institutions, in order to house the increasing numbers, and to ‘provide for’ the often unmet needs of identified populations (Kliewer & Drake, 1998). Finally, tests such as these, and other quantifiable measures, have historically carried profound influence in policy decisions regarding people with intellectual disabilities. The current assumptions with which administrative regimes make decisions on behalf of people with disabilities is rooted, at least in part, in the historical period spanning the turn of the twentieth century, during which there was immense interest in the categorical power generated by scientific and progressive theory (Kliewer & Drake, 1998; Pfeiffer, 1994).

The trends discussed above—that is, the impulse towards a ‘norming’ of the population, and the increasing interest in intelligence testing as a way to efficiently categorize people in order to make decisions regarding “adaptation [or]... elimination” (Goddard, 1920 [1914], p. 3)—underscore the link between discourses of normativity and eugenic thinking. Indeed, the next step in the thrust of social progress included eugenic discourse and praxis (Davis, 2010, Trent, 1996), another trend which has had significant implications in the segregation of people with intellectual disabilities.

Eugenics: “sterilization versus segregation” (Radford, 1991)

As statistics and intelligence testing gained momentum at the turn of the twentieth century, the idea of their applicability towards the improvement of human genetic stock achieved credibility. Davis’ (2010) assertion of “a symbiotic relationship... between statistical science and eugenic concerns” (p. 7) affirms the new enthusiasm for measurable data about human capacity and the possibility of eliminating unwanted traits in the population. Mackenzie (1981) describes the obligatory nature of this relationship in his contention that it was not so much the collection of statistical data that enabled eugenic praxis, but that “the needs of eugenics in large part determined the content of ... statistical theory” (p. 52). That is, “eugenics informed and guided... statistical theorising.... and conditioned the content of it” (p. 68). Thus, Mackenzie asserts, statistics were not simply objective measurements of the characteristics of a given population, but were influenced by socio-political conditions which promulgated the discourse of the need for a strong and capable populace. While a comprehensive discussion of eugenic practice and its implications, both historically and currently, is not possible here, a brief examination is warranted because of the contribution that eugenic theory has made in the segregation and institutionalization of people with intellectual disabilities.

The term “eugenics”, or “well or truly born”, was first coined in 1883 by Sir Francis Galton (1822-1911), the British statistician and advocate of genetic determinism mentioned above. Galton was a firm believer in the ranking of individuals according to desirable traits, and was a leading figure in public health policy which was designed to encourage the proliferation of ‘desirables’ (positive eugenics) and the eradication of ‘undesirables’ (negative eugenics). Eugenics was redefined in 1910 by an American, Davenport, as “the science of the improvement

of the human race by better breeding” (Davenport, 1910, as cited in Allen, 1997, p. 78), a definition which lent the field a more scientific and positivist validation.

Eugenic practices which were employed with the ‘feeble-minded’ in North America in the early part of the twentieth century consisted primarily of segregation or sterilization (Radford, 1991). As Radford (1991) notes, the practice of placing people with intellectual disabilities in institutions, besides barring them from any potentially meaningful participation in productive society, served as a “eugenic instrument” (p. 456) by minimizing the possibility of interaction between the sexes. Indeed, Walter Fernald, “a leading figure in the institutionalization movement” (ibid, p. 453) referred to institutionalization as “strict sexual quarantine” (ibid), a method that, although bearing the same intentions of sterilization, seemed a more palatable approach to several segments of the general population (McLaren, 1990). This did not prevent, however, the liberal and legal application of sterilization in both Canada and the United States during this era, and indeed until at least 1972 in two Canadian provinces, when sterilization acts against the ‘feeble-minded’ were finally appealed.⁸ Moreover, there were significant yet often unscientific, rhetorically-based arguments for the use of sterilization from all corners of the social progressionist camp (Allen, 1997; Harris, 2011; Kennedy, 2008; McLaren, 1990; Pfeiffer, 1994; Radford, 1991). Lamp (2005), for example, notes that while sterilization was frequently couched as a liberatory tool for the emancipation of women by some of the first-wave feminists in the United States, the underlying purpose was to limit reproduction within particular groups, most notably, “hopelessly, inherently dependent defectives” (para 4).

Besides the fundamental moral concern here, that is, by definition, the gradual elimination of entire groups of people within a population in order to raise the normative standard of physical, intellectual, and emotional capacity, there are other elemental threads

stemming from eugenic discourse which are relevant to our understanding of the development of institutions for people with intellectual disabilities. First, eugenic thinking overlaps with what was considered progressive thinking at the time. Indeed, many scholars have discussed both the philosophical underpinnings of eugenic policy, and its entrenchment within ‘progressive’ Canadian and American discourse (Allen, 1997; Harris, 2011; Kennedy, 2008; McLaren, 1990; Pfeiffer, 1994; Radford, 1991). Intellectuals and visionaries who had no small amount of influence on policy decisions imagined a more just and utopian society, “in which disease and degeneration would have no place” (McLaren, p. 166). In this era, just prior to the discovery of antibiotics, when people were aware of the devastating and far-reaching consequences of illness and disease, this seems an understandable sentiment. Indeed, the presupposed trajectory of improvement of the human condition through social and political means was in many ways an inevitable discourse in light of previous centuries’ suffering, and with the growth of scientific and medical disciplines (Jonsen, 2000; Porter, 1997). Moreover, eugenicists believed that medical procedures and policy based on ‘science’ could be justifiably employed to deal with a breadth of social ills, (McLaren, p. 169), including large numbers of “deformed, subnormal” children (Sanger, as cited in Lamp, 2006, para 24), overcrowded slums, criminality, and a generalized lack of moral fortitude (Harris, 2011; Kennedy, 2008; Lamp, 2006; McLaren, 1990). Eugenics was seen as a “biologically based program of reform” (McLaren, p. 105), a humane and just way to further the general wellness of the population. Further, eugenic programmes were seen as possible solutions to the notable upheaval and unrest—in particular, increasing urbanization and its accompanying vices—which emerged in the early decades of the twentieth century (Allen, 1997; Kennedy, 2008) and were considered threats to the moral fabric of early Canadian and American society (McLaren, 1990).

What is of concern here is not only the existence of the abhorrent and unjust practices put into place through eugenic theory, made increasingly more visible via the power of retrospection. Equally concerning are the ever-shifting definitions and boundaries of ‘progressive’ social policy, and the profound implications these have had, and continue to have, on people with disabilities. That is, the tension between the socialist mores within which eugenics were couched, and current understandings of their inadmissibility, reveals the pliability with which disability is defined, shaped, and ultimately acted upon according to current cultural norms and aspirations. This is a critical point within disability scholarship, and while the shifting nature of discourse concerning disability has been discussed by some authors (see, for example, Bogdan, 1988), it is my contention that this needs further attention. Understanding disability through the entry points that history provides, and using the resulting insight to affect change might therefore be seen as equally important as noting the undeniably horrific practices of the past. Such retrospective allows an appreciation for the shifting nature of the discourse within which progressive visions are articulated, and their resulting impact on affected populations. Moreover, it reminds us of the utopian and reformist nature of the initial visioning surrounding institutionalization: were that the original designers might have foreseen the long-term and dire results.

A second observation which stems from the discourse surrounding eugenic thinking is its transhistorical emergence at times of social and political unrest (Allen, 1997; Harris, 2011; Kennedy, 2008; McLaren, 1990). In the same way that Girard (2001) points to the historic use of the ‘scapegoat’ during times of communal strife in order to ensure the return of order, Shildrick (2002) notes that “the grasping after an order of explanation in the face of extraordinary corporeal disruption is an enduring feature of historical record” (p. 20). While our discussion here does not revolve necessarily around the “extraordinary corporeal disruption” to which

Shildrick refers, the justification for eugenic practices was consistently couched in rhetoric which ascertained the need to implement and maintain order in both the new colony (Canada) and republic (the United States). As such, during the time period with which we are concerned, eugenic praxis was most frequently instigated under the precepts of bringing stabilization to an uncertain economic and moral climate. Allen (1997), for example, notes that the efficiencies of human resources which eugenics promised fit perfectly into the mold of “scientific planning and management” (p. 83) being applied to economic and industrial undertakings. Further, Kennedy (2008) notes that within the conclave of the ‘wellborn’, “various manifestations of mental deficiency, moral deficiency, and social inadequacy” (p. 24) were seen as indicators of the general destabilization which accompanied the urbanization and modernization of the early twentieth century, and affirmed the need for strict population controls.

A final observation from eugenic discourse worthy of our attention here is that eugenics consolidates the putative assumption that there are people who require, and always will require, others to speak on their behalf, and that these representatives will always speak in others’ best interests. Until very recently, and still now to a large degree, people with intellectual disabilities have not been the primary actors in decision-making regarding their own lives, and have historically had almost no input into decisions affecting where and with whom they live. Eugenic practices consolidated this lack of control to the most extreme measure, and while institutionalization is more frequently analysed as a method of medical management and family respite, it was, in essence, an effective eugenic tool, used to prevent the ongoing proliferation of the ‘feeble-minded’. Further, what remains contentious within the historical acceptability of speaking on behalf of persons considered intellectually challenged is the flexibility with which the parameters of well-being and suffering are articulated.

The above discussion of the eugenic period, although brief, is important to a contextualized understanding of institutionalization, as it demonstrates the embeddedness of institutionalization within eugenic discourse as a means towards control and prevention of the furtherance of ‘feeble-mindedness’. As Trent (1994) notes, “the linkage of sterilization with both segregation and heredity was complex” (p. 295), and a grasp of this involvedness is helpful in understanding the factors at play in the establishment of institutions as a principle method of dealing with an increasingly unwanted population.

Conflating Factors

The eugenic and normative concerns which proliferated at the turn of the twentieth century constituted a discursive loop which informed decisions regarding the ‘feeble-minded’. This discourse was enhanced with arguments concerning the threat posed by several allegedly interconnected populations, all of which were seen as evidence of the need to institute segregative policies. A principal contributing discourse in this intersection of conflated identities is that of the immigrant, or, specifically, the immigrant whose potential contribution to Canada’s developing economy and identity was seen as questionable. The “foundational narrative of Canadian nationhood” (Thobani, 2007, p. 33) is often presumed to include generous immigration policies which have encouraged welcoming populations willing to overcome the barriers inherent in settling a harsh land, a discourse which has become embedded in the colonial Canadian narrative (ibid). Simultaneously entrenched within this discourse, however, is the assumption that only particular immigrants are desirable and capable of reproducing the essential tenets of the nation state (ibid, p. 62). Thus, while Canada’s official interior policy relied heavily on immigration to turn aboriginal territories into productive farmland (McLaren, 1990), there were simultaneous restrictions on the kind of immigrant who was welcome (Chadha, 2008;

Menzies, 1998). As Chadha (2008) points out, as early as 1869 the “prejudicial roots” (para 3) against the admission of people with disabilities were firmly entrenched within Canadian immigration law. Chadha notes that judicial and political mechanisms were established to “secure immigrants of higher physical and mental quality” (para 31), and that “the expanding category of the ‘mentally unfit’ immigrant was contemporaneous with the rise of psychiatric and eugenic science and the increasing medicalized demarcation of mental conditions and intellectual classifications” (ibid). Further, scholars suggest that the racist biases exhibited against immigrants from less-desirable countries, that is, those of non-Anglo-Saxon origins (Chadha, 2008; Kennedy, 2008; McLaren, 1990; Menzies, 1998), were readily collapsed into a more comprehensive categorization of the incompetent in general, thus providing officials with ample justification for the deportation of less desirable immigrants, citing ‘feeble-mindedness’ as the rationale. The observations of McRuer, a twenty-first century disability scholar who has critiqued current immigration policies’ intersection with ableist assumptions, are thus eerily relevant when we examine a statement by Henry Esson Young, a Canadian immigration official who voiced his opinion against generous immigration schemes almost a century earlier. While McRuer (2006) points to the ‘disposable’ nature (pp. 203-207) of the immigrant / disabled identity within the context of current economic regimes, Young (1920) in the throes of an era of restrictive measures against the admission of particular groups of people, noted

The human being is beginning to be looked on not as an individual altogether independent from other individuals and from the community, but as an economic unit of the community who has a very definite productive value (cited in Menzies, 1998, p. 139).⁹

What is of concern here is the ease with which governing bodies have been content to conflate categories of apparent social ineptitude in order to address the assumed menace of the ‘other’. Beyond the limits placed on immigrants originating from less than desirable countries, people of lower socio-economic status, as well as people considered to be suffering from ill health, delinquency, and madness, were all presumed threats to the strength of Canada as a nation during a prolonged era of nation-building and patriotism, and were conflated with a categorical assumption of inadequacy. The ‘lowering’ of the standard, so to speak, of potential contributors to the Canadian fabric by subsuming them under the umbrella of disability was a politically justifiable way to control the constitution of its citizenry (Thobani, 2007).

Conclusion

The trends discussed in this chapter provide a historical contextualization for the rise of institutional practices in North America. While the first part of the chapter discusses the charitable impulses which shaped some of the earliest configurations of institutions, the normative and eugenic perspectives addressed in the latter sections demonstrate some of the more disreputable developments of the modern and progressionist thinking which predominated the social and political landscape at the turn of the twentieth century. The situation was ripe for the securing of institutions as an economically feasible and morally ‘necessary’ solution for the placement of unwanted and seemingly unproductive, potentially dangerous segments of the population.

Chapter Three: The rise of institutions in North America

Introduction

This chapter will examine the establishment of institutions for people with intellectual disabilities in North America in the late nineteenth and early twentieth centuries. Its purposes are three-fold. First, I will attempt to provide a chronological tracing of the development of institutionalization in the time period specified. This discussion will be preceded by a brief exploration of the irony inherent to this undertaking. Second, institutionalization will be examined as a justification for the increasing professionalization of care for people with disabilities during this era, revealing the symbiotic and self-sustaining relationship between institutionalization processes and the rise of particular forms of specialized care (Trent, 1994). And finally, institutionalization will be briefly examined by means of a class analysis, wherein institutionalization can be seen as an example of the “maldistribution of resources, status, and power” (ibid, p. 5) which has persistently marked the lives of people with intellectual disabilities. While this chapter strives to provide a historical understanding of the rise of institutions specific to North America, it will also draw from scholarship which has emerged from the United Kingdom, due to the significant contribution this work has made to our understanding of institutionalization processes.¹

Chronology / ‘Flexibility’

While historical excavations are often undertaken using a chronological approach, some scholars in the field suggest that a thematic and multifaceted methodology, as opposed to a linear one, is more appropriate (Radford & Park, 1993a). Persistent and transhistorical fluctuations in interpretations of disability suggest that a strictly sequential and progressionist approach is inadequate and potentially misleading. Accordingly, this section is a brief examination of the

need to remain attentive to disability's historical subjection to political and cultural interpretations from relevant time periods, and how this has had an impact on the way in which the histories of people with disabilities have been written and understood.

Radford & Park (1993a) note that a “stage model” (p. 374) of investigation can “force analysis into a unilinear path” (ibid), and that a more comprehensive perspective is gained by examining relevant historical policies and the philosophies undergirding their implementation. Moreover, they suggest embracing the “palimpsest” approach proposed by Simmons (1982, pp. 41-48), a model which situates, in historical ‘layers’, the philosophical frameworks relevant to particular time periods in the development of institutionalization. Simmons’ analysis provides a rigorous rebuke to a progressionist approach, as it encourages historical excavation of each ‘layer’ of the variant models of care which were predominant at different periods in the development of institutions. Most importantly, his method, which will be examined in closer detail in a later section, suggests that policy fluctuations observed in the shifting palimpsests did not necessarily correspond to improvements in the lives of people in institutions who were subjected to their implementation.

Simmons’ and Radford & Park’s call to exercise caution towards progressionist models is echoed by other scholars. Scull (1979), who notes in detail the materialist, “secular rationalist” (p. 42), and scientific impulses which facilitated the rise of institutionalization in Victorian England, further contests the notion of a positive progression in the institutionalized care of people with identified disabilities. Scull notes that while interpretations of the historical transformation of institutionalized care of mad people is often framed within a reformist agenda, he, too, suggests that the shifts in care in the nineteenth century had much more to do with their materialist and capitalist underpinnings than with a broad and sympathetic cultural concern. This

is not to deny that throughout the development of institutionalized care there existed some social concern for improvement in the lives of people with intellectual disabilities. These concerns have, however, been, for the most part, usurped by goals of efficiency and control as dictated by growing capitalist economies in both the United Kingdom and North America, and by the general scientific movement towards the classification and categorization of individuals according to ability (Rothman, 1971; Scull, 1979; Trent, 1994).

This anti-progressionist sentiment has been furthered by disability scholars, who note that the disabled subject has historically been treated as a flexible entity, vulnerable always to fluctuations in political and cultural discourse. Mitchell's (1999) introduction to Stiker's *History of Disability*, is a reminder to remain committed to countering "cultural progress narratives" (p. vii), while simultaneously being astute to "key moments in the *revision* of disability's meanings" (ibid, p. ix, emphasis added). Further, Shildrick (2002) observes that while the "standardising impulses of modernity and the positivism of science [may] signal an epistemological break in the response to the monstrous" (p. 23), this does not necessarily imply that a steady and straightforward approach to analysing historical developments can be adhered to. Indeed, Shildrick suggests, shifts in interpretations of disability tell us more about the "social and political uncertainty" (p. 20) underlying particular historical moments than they indicate increasing awareness of the conditions of the lives of people with disabilities. She proposes not an assumed "narrative of progressively more adequate understanding" (p. 25), but rather an appreciation that "reality and fantasy are always in tension" (ibid). These arguments suggest an always-cautionary approach to the historical tracking of the lives of people with disabilities, and to the responses which have been offered throughout.

Despite these concerns, I remain committed to an attempt to map the historical development of institutions in North America in a fairly chronological fashion, if only to provide some delineation with which to trace the phenomenon. For the purposes of this discussion, I have divided this history into three somewhat distinct eras: the beginnings of the institutional era in the early nineteenth century; the era of the establishment of institutions in the mid-late nineteenth century; and the era of consolidation of institutionalization in the late nineteenth and early twentieth centuries. While I have done so because of time-specific themes that seem to appear at these particular junctures, there exists, of course, a certain amount of arbitrariness to the divisions between each time period, and overlap between them. This examination will reveal the unfortunate route that institutions have taken in North America: while the original intentions for their establishment might have been worthy under the reformist objectives of the mid-late nineteenth century, these intentions gradually but steadily deteriorated such that institutional care became solely a geographic and social site for the incarceration of those with intellectual disabilities.

Historical chronology

Early nineteenth century: Family as the locus of care

Scholars suggest that prior to the mid-nineteenth century, the care of people considered disabled, vulnerable, and even deviant within mainstream society had been absorbed primarily by the family (Chupik & Wright, 2006; Ferguson, 1994; Richards, 2004; Rothman, 1971; Scull, 1979; Stiker, 1999; Trent, 1994; Tyor & Bell, 1984). While there is no question that certain individuals might have been considered disruptive and whose needs might have been difficult to meet beyond immediate familial resources, it appears that the family was the principal site of support and concern. This observation is consistent across varying geographic locations and

among people with a range of corporeal and intellectual differences. Thus, for example, while Trent (1994) and Rothman (1971) describe the extent to which families took responsibility for members with intellectual disability in early nineteenth-century America, Scull (1979) makes a similar claim regarding the care of mad people during the same time period in the United Kingdom, and Stiker (1999) provides a comparable observation for the primarily ad-hoc and family-centred care given to people with disabilities in pre-modern France. While each of these scholars addresses different groups of people in different geographic locations, evidence suggests that prior to the emergence of some of the more influential arms of modernity—the rise in industrialisation and the subsequent need for a skilled workforce, the “commercialization of agriculture” (Scull, 1979, p. 20), and the rapid increase in an urbanised population—care was primarily unsystematic, broad, and family-centred in nature (ibid, p. 18).

The lack of rigorous categorization of people who lived a marginal existence during this time period also contributed to an improvised approach. Scholars suggest that prior to the development of the broad social structures which became the hallmarks of modernity, as well as the corresponding policies inherent therein, there existed a generalized ‘lumping together’ of various forms of deviancy (Rothman, 1971; Scull, 1979; Stiker, 1999; Trent, 1994). Those living on the margins of existence would have included people with visible disabilities, people considered mad, those who were indigent or unable to find meaningful work, women in many cases, and those considered deviant through criminal activity. This began to shift, however, with the growing distinction, which grew markedly in the nineteenth century, between the able-bodied and non-able-bodied poor, a phenomenon in close alignment with the increasing demand for a competent work force to fulfil the demands of the new market economy (Scull, 1979, pp. 36-37). Gradually, “the functional requirements of a market system promoted a relatively simple, if

crucial, distinction between two broad classes of the indigent” (ibid, p. 40). As the distinction between those with productive potential and those without gained momentum, and the expectations of the market economy became increasingly more demanding, the “traditional, family-based response... was beginning to be abandoned” (ibid, p. 26), and the “assumption of state responsibility” (ibid, p. 45) via the auspices of an institutional response, began to be realized.

Mid-to-late-nineteenth century: The establishment of the modern institution

Thus, from the mid-nineteenth century onwards, the care and concern for people considered burdensome gradually moved from a haphazard, localized, and family-centred approach, towards a response which was increasingly state-directed, within which institutions began to be used as a primary organising and intervention tool (Ferguson, 1994; Tyor & Bell, 1984; Rothman, 1971; Scull, 1979; Trent, 1994). The social and economic conditions of the mid-1800s, in combination with the reformist ideology which was beginning to emerge on both sides of the Atlantic, set the stage for the establishment of institutions and institutionalized care. Accordingly, two principal features will be addressed here.

First, and already briefly discussed, was the intersection between the demands of the growing industrialised, urban economy, and the increasing distinction between those considered able to contribute productively to the market, and those considered incapable of such participation. Scull (1979), whose work thoroughly summarizes this development in the United Kingdom, notes that the deviant, particularly the mad, were increasingly seen to hinder the potential productivity inherent to capitalist industrialism. He notes that “order and discipline” (p. 41) required by the burgeoning workhouses were “threatened by the presence of a madman” (ibid), and that institutions provided a convenient, invisible, and orderly site of confinement

within which to contain possible sources of social and economic disruption. Trent (1994) notes a similar shift in the perceptions of people with disabilities in mid-nineteenth century America, also in accordance with changes in the productive expectations of individuals in the growing American economy. In particular, Trent notes the shift in acceptability after the American Civil War (1861-1865), a time period of increasing industrialisation within which the presence of disability was seen as “a hindrance to the social and productive order” (p. 59).² As such, “attaining a respectable mediocrity on the family farm or in a local small shop” (ibid) became less appealing in the post Civil-War American social fabric, and communities began to reject the notion of the obligation to accept the “idiot, even educated ones” (ibid).

The second feature which consolidated institutionalization as a noteworthy phenomenon in the nineteenth century were the intentions of leaders in the reformist movement, which sought to address the ‘problems’ of ‘feeble-mindedness’ and ‘madness’.³ While the notion of reformism was theorised briefly in the previous chapter’s discussion of eugenics, it re-emerges here as a decisive factor in the establishment of the institutions with which this project is concerned. While the notion of reform could theoretically be understood as a gradual, even centuries-long transition in the response to marginalized populations, including the sanctioning of state support through Britain’s Poor Laws of 1601, the reform with which we are concerned here is the more specific shift in the mid-nineteenth century from a response based on revulsion and fear, to one more firmly grounded in the impetus to improve the lives of people on the edges of society (Scull, 1979, p. 65). Market capitalism lessened the notion of the world being “divinely authored” (ibid, p. 70), and increased the notion of people’s active and rational contribution to the manufacturing process, to the control and transformation of nature from raw material into manufactured and purposeful objects. Accordingly, there existed “parallel contemporaneous

shifts” (ibid, p. 71) in perspectives towards mad and disabled people—from the notion that these were members of society who were not quite human (ibid, p. 68), to those who could be transformed or “remodelled into something approximating the bourgeois ideal of the rational individual” (ibid, p. 69).

This shift was originally manifested in the movement to improve the abhorrent conditions which existed in ad hoc, privately-run ‘mad houses’ which had sprung up in the early decades of the nineteenth century in the United Kingdom (Scull, 1979, pp. 50-54), and in the establishment of educative and curative facilities for the ‘feeble-minded’ in the United States (Ferguson, 1994; Trent, 1994; Tyor & Bell, 1984).⁴ By the middle of the 1800s, reformism signified the establishment of state-run, government-supported institutions and asylums, originally intended to provide a safe, restorative environment within which individuals could be restored to full health (in the case of mad people), or could be trained or habilitated (in the case of the intellectually disabled) in the hopes of an eventual and successful return to meaningful roles in the community (Rothman, 1990[1971]; Trent, 1994). Indeed, as Radford & Park (1993a) note, the original intention of the early Victorian “reformers” (p. 371) was to “prepare...‘idiot’ children for productive lives in the outside world” (ibid). That this ideology underwent several marked and degenerative transitions between the mid-1800s and the turn of the century does not take away from its original, ‘optimistic’, if misguided, purpose.

In North America, the mid-nineteenth century marks the decisive implementation of institutions for the feeble-minded, in the United States in particular. Rothman (1990[1971]) notes that several states had already established ‘insane asylums’ prior to the Civil War (p. 130), some as early as the 1830s, thus indicating that the movement towards segregation had already begun. However, a growing belief in the power of education to transform individuals into productive

members of society, the opportunity to fulfil one's moral obligation to assist other members of the community, as well as the nascent acknowledgement of the rights of all people to attend school, lead to a rapid increase in the particular establishment of institutions for the 'feeble-minded' (Ferguson, 1994; Trent, 1994). As Tyor & Bell (1984) indicate, reformist ideology was instrumental to this development: "Underlying all these points was the perfectionist faith of many reformers that there was no limit to the improvement of humanity, and no barrier that could not be overcome with the proper application of faith, hard work, and knowledge" (p. 15).

The work of Eduard Seguin provides a good example of the establishment of institutions for the 'feeble-minded' during this time period, as well as the eventual shift in intentions underlying their purpose. Seguin immigrated to the United States from France in 1848, having already worked with children with intellectual disabilities, and having already written a widely-read text on his approach. Seguin arrived with a willingness to establish a particular pedagogy which included physical activity, education of the senses, and 'moral treatment'. Besides traditional physical rehabilitative measures, Seguin believed that intervention must include a regime of tasks geared towards the development of "moral volition" (Tyor & Bell, 1984, p. 9) and upstanding will. Indeed, Seguin's emphasis on 'moral treatment' is reflective of prominent thinking at the time, firmly and broadly grounded in the popular imagination, that the real cause of the disabilities inherent to feeble-mindedness was a lack of moral fortitude, and an "arrested development of the will" (Trent, 1994, p. 46). This "moral idiocy" (ibid, p. 23), however, could be controlled efficiently and effectively with "the guidance, care and restraint of the institution" (ibid). Institutional living and residential education would transform individuals previously burdened by intellectual handicap, into "free men and women" (Trent, 1994, p. 52), capable of

returning to their home environments as upstanding citizens. Seguin's work was extremely influential in mid-nineteenth century North America, so much so that little other work was initiated in the field during this time period (Tyor & Bell, 1984). Moreover, it lent credibility to the institutional training school as a place of progressive change, wherein the burdensome and unproductive 'idiot' could be transformed, through the disciplined application of education and guided activity, into a productive member of society.

It was during this era of hopeful optimism that several institutions for the feeble-minded were established in North America. Indeed, there was a burgeoning of activity, as residential educative facilities were built with the intention of providing the most current education and training (Ferguson, 1994; Simmons, 1982; Trent, 1994; Tyor & Bell, 1984; Williston, 1971). Ferguson (1994) observes that historical records indicate widespread approval of the philosophy and application of moral treatment, and depict this era "as one of enlightened care and active treatment or education" (p. 49). These developments, and their corresponding philosophical underpinnings, solidified the establishment of institutions as a humanitarian and worthwhile response to a population with the potential for productive and meaningful societal participation, if only given timely and appropriate care. It is important to note that at this initial stage of development, institutions were built to "function strictly as schools, not as custodial asylums" (Tyor & Bell, 1984, p. 21). Several features of their early practice ensured that the "rehabilitative ideal" (ibid, p. 22) was maintained, such as ongoing contact with the family and community, strict admissions policies, and an overall optimistic "faith in the perfectibility of man" (ibid, p. 21).

The vast majority of this activity was centred in the northeastern United States (Radford & Park, 1993b). While a comprehensive list of the institutions established during this time period are too numerous to list in great detail here, their rapid increase in numbers, as well as the

optimistic idealism within which they were framed, is notable.⁵ In 1876, this movement spread north of the border and the first large, government-supported institution of its kind in Canada, the Orillia Asylum for Idiots, was established (McLaren, 1990; Radford & Park, 1993a, 1993b). As we shall soon see, however, the Orillia institution benefitted little from the idealism and optimism which had marked the early American projects, as it was established during an era when the intentions underlying their establishment had already begun to change.

Despite the optimism held by the founders and supervisors of these early institutions, their formative objectives began a lamentable shift in the latter half of the nineteenth century. The edges of the ‘helpful’ intervention and sound philosophical tenets with which the institutional movement had begun in North America began to fray, to such point that by the end of the nineteenth century, the “original inspiration for the early institutions” (Radford & Park, 1993a, p. 375), was more or less “obliterated” (ibid). Institutionalization moved from a rehabilitative and regenerative model to one based solely on custodial care, and the incarceration of the intellectually disabled population moved into what I perceive as the third stage, the consolidation of institutionalization, one that remained firmly in place until the 1970s (Trent, 1994).

Late nineteenth century, early twentieth century: The consolidation of institutionalization.

By the end of the nineteenth century, the central, organizing philosophy embraced by institutions for the feeble-minded had shifted from an ideal of hopeful regeneration to one of long-term custodial care. Simmons’ (1982) palimpsest model, introduced earlier, is a helpful framework within which to begin this discussion and to understand the social conditions which altered the purpose and vision of institutions. Simmons suggests that the original intention to

educate the ‘feeble-minded’ in order to ensure their successful return to the community gradually shifted, in conjunction with the rapid increase in industrialization, to an *asylum* approach which claimed that people with intellectual disabilities should be removed from the mainstream for their own protection, “on the grounds that they were not able to compete effectively in modern society” (Radford & Park, 1993a, p. 375).⁶ This *asylum* mindset, in turn, began to shift as the principal organizing features of modern society turned to the notion of social progress and improvement, which included the removal of the intellectually disabled from all aspects of public life. Simmons names this the “*social control approach*” (p. 44), and is the beginning of a more fearful era in the interpretation of feeble-minded people, prescient of the eugenic era. Finally, by the early years of the twentieth century, the philosophy had moved decisively into the *custodial* model which remained firmly in place for the next eighty years. In general, this era was marked by reasoning which suggested that the placement of individuals in institutions was for the “supposed protection of society” from the dangers of the feeble-minded (Radford & Park, 1993a, p. 374).

There are several reasons for the shifts outlined by the palimpsest approach. First, as public awareness of institutions grew, superintendents gradually became subject to mounting pressure to admit increasing numbers of ‘feeble-minded’ people, as well as “those with more complex emotional or physical problems” (Simmons, 1982, p. 43). As public pressure mounted to admit more individuals, the population and needs of those residing in institutions increased, and superintendents began to “acknowledge the need for custodial [care] alongside educational programmes” (Trent, 1994, p. 29). Further, the corresponding need for an increase in necessary resources did not materialize, and institutional care gradually slid, partly through necessity, into a custodial model. Second, it became increasingly evident that the “ambience of success and cure

that was part of the reformist spirit” (Ferguson, 1994, p. 56) within which institutions had initially been established was neither accurate nor sustainable. Indeed, some of institutionalization’s earliest adherents began to state the need to not overestimate the rehabilitative potential of institutional care due to the incurable nature of feeble-mindedness (Ferguson, 1994; Tyor & Bell, 1994). Acknowledgement of the lack of ‘cure’ of the ‘feeble-minded’ led to a deflation of the optimistic vision for institutions the early reformers had once articulated, and encouraged the development of long-term, custodial-type facilities (Trent, 1994). Further, as Ferguson (1994) notes, a philosophical tension between “chronicity” and “curability” (p. 53) began to emerge at this time in theoretical and political discussions, a debate which was ultimately not resolved so much as it was allowed to slip into what essentially became custodialism, the seemingly simpler, and cheaper, form of intervention.

Third, the medicalization of ‘idiocy’, which began to take place during this era, solidified the shift from an educative model to a custodial one. Administrative needs moved from educators to doctors and superintendents, with a dependence on “medical practice, medical institutional structure, and medical paradigms” (Trent, 1994, p. 36). The needs of this new vision were better met by asylums than schools, for the needs of the sick were better met in large, medically-serviced institutions, and “a sick idiot fit a custody model better than did an educated and productive one” (ibid, p. 38). Last, there were financial reasons for the move from an educative model to a custodial one. It soon became evident that educated ‘idiots’ could return to family or community only “when economic conditions were good” (ibid, p. 38). As there was little in the way of public support at the rural or local community level except for the almshouse (Ferguson, 1994; Tyor & Bell, 1984), a custodial, institution-based model of care became the

simpler, more-easily-administered, and least expensive method for caring for the feeble-minded near the end of the nineteenth century.

There are additional factors which contributed to the strengthening of a custodial model of care during this time period. Many of these were discussed in the preceding chapter as contextual factors which assisted in the establishment of institutions, and fall under the rubric of the late-nineteenth-century obsession with the betterment of the human race through eugenic practices, intelligence testing, and the segregation of school children based on arbitrarily-assessed academic potential. Indeed, as current scholars have indicated, the progressive narrative of modernism facilitated the segregation (and sterilization) of people with intellectual disabilities through all of these channels, which often worked in synchronicity and in support of each other (Allen, 1997; Chupik & Wright, 2006; Kliwer & Drake, 1998; McLaren, 1990; Strong-Boag, 2007). For example, the rapid ‘discovery’ of ‘feeble-mindedness’ and ‘morosity’ in school children as public schooling became mandatory around the turn of the twentieth century (McLaren, 1990, p. 38) lent credence to the zealous work of Helen MacMurchy, a Toronto public health official whose primary goal was to eradicate the so-called threat to public health contained within the ever-expanding ‘feeble-minded’ population by calling for an increase in segregation and sterilization practices in the early years of the twentieth century (ibid, p. 29). Through the work of MacMurchy alone, several hundred women and children were referred to the Orillia Asylum (ibid).

Further, institutions simply provided a “convenient” method of dealing with an increasingly troublesome population (Radford & Park, 1993a, p. 369). Although eugenic practices were officially implemented in various parts of North America (Allen, 1997; Pfeiffer, 1994; Radford, 1991), including the Canadian provinces of Alberta in 1927 and British Columbia

in 1932 (McLaren, 1990), they were not welcomed in all jurisdictions (McLaren, 1990). The rejection of outright eugenic policies in Ontario and Quebec meant that the threat of a growing ‘feeble-minded’ population needed to be dealt with using other means, and the strict segregation between men and women at institutions provided an opportune solution.⁷ Despite the persistent lack of funding and increasingly crowded conditions (Simmons, 1982), institutions were still regarded as a favourable solution to the “burden of the feeble-minded” (Simmons, 1982, pp. 65-109; Trent, 1994, pp.65-109).

Accordingly, admission rates to government-run institutions for the feeble-minded increased rapidly during the latter half of the nineteenth century, and historical data suggests that this trend existed on both sides of the border (Simmons, 1982; Williston, 1971). By the turn of the twentieth century, the institution was a well-established tool within the Ontario government’s arsenal in its battle against the seemingly growing wave of individuals unsuited and incapable of modern life, and the admission rates at government-run institutions continued to rise throughout the twentieth century (Radford & Park, 1993a, 1993b; Simmons, 1992; Williston, 1971).⁸ Indeed, little changed in the ideological and practical approach to people with intellectual disabilities from the turn of the twentieth century until deinstitutionalization became a serious philosophical and political consideration in the 1980s (Ferguson, 1994; Simmons, 1982), and the “institutional structure that had been established between 1890 and 1920” (Trent, 1994, p. 130) remained firmly in place.

Institutions and the justification of professionalism

Scholars suggest that there was a great deal more at play in the movement to consolidate the institutionalization of people with intellectual disabilities than the philosophical tenets of education, asylum, and segregation. Undergirding these more blatant discourses, which were

admittedly the more predominant and directive arguments in the case for increasing and maintaining the capacity of institutions, was the rhetoric of need for various specialised roles that grew out of, and were then justified by the existence of institutions. Educators initially (Gould, 1996; McLaren, 1990; Trent, 1994), then social workers (Kennedy, 2008), occupational and physiotherapists—all owe a significant portion of their professional development to the forces at work in the social construction of the incapacities of the ‘feeble-minded’, and their need for expert intervention.

This trend to discursively enhance the limitations and menace of ‘feeble-minded’ people, as well as the need for professionalized care in order to reduce their threat to the general population is a thread which has been discussed by various scholars (Scull, 1979; Noll & Trent, 2004; Trent, 1994). While their analyses address different time periods and variant locations, the commonality of this theme suggests that this is a feature inherent to many examples of institutional development. The observations of Trent and Scull regarding the geo-political construction of disability—that is, the discursive production of the needs of people with disabilities, the physical sites created within which to house them, as well as the corresponding construction of services required to provide for them—are fundamental tenets within their theoretical frameworks. Indeed, Trent (1994) regards this as an essential element within the history of the institutionalization of people with intellectual disabilities in the United States. He suggests that current awareness of the self-sustaining mechanisms inherent to the professionalization of care is critical to a complete understanding of past processes. Trent (1994) notes: “superintendents and social welfare agents... reshaped the contours of both care and control to ensure their personal privilege and professional legitimacy” (p. 5). In his work, Trent provides exhaustive detail concerning the movements and decisions of the supervisors, educators, and politicians who worked symbiotically to build an incarceration system so complex that it required the

retention of its founders and original visionaries, as well as a veritable army of trained professionals, in order to maintain itself. Likewise, Scull (1979) notes that the emergence of professionals at the peak of the reformist movement to establish institutions in the latter half of the nineteenth century instigated a “self-reinforcing system” (p. 44). He suggests this is a “dialectical process”, within which the relegation of the deviant into asylums “helped create the conditions for the emergence of an occupational group laying claim to expertise in their care and cure” (ibid). Thus, once the surface of history is scratched, the dependence of ‘helping’ professions on the ongoing production and maintenance of the populations they were intended to serve is revealed.

Goffman (1961) elides this justification with the larger socio-political irony within which institutionalization is embedded. That is, the institution works only when there is sufficient distance between the powerful (administrators) and the powerless (residents); should the distinction between the two begin to disintegrate, the self-sustaining mechanisms of institutional arrangements would no longer be valid. This is not dissimilar to Foucauldian theory, which draws attention to the discursive production of the disciplinary practices created to deal with deviance, which indeed play a key role in the creation of the meaning attached to deviant individuals themselves. That is, a progressionist or even chronological historical record might suggest that the creation and maintenance of institutions occurred in response to deviance; Foucault (1977) inverts this presumption and suggests that the construction of deviance is more a function of the need to complete the modernist picture of state control and governance. In short, the economics of power, and the supervisory arrangements that Foucault suggests is ubiquitous in modern social arrangements, creates the categorical deviance that modernity seeks always to address.

This self-reinforcing feature of the modern institution and its related professionals has had indubitable effects on its historiography. Kennedy (2008), for example, notes that social work emerged

not only as a profession to meet the needs of a growing poor population at the turn of twentieth century America, but was a key player in the discursive shaping of the very group it was meant to serve, “shaping public discourse...and state and federal public policy” (p. 22). The professions which have emerged from institutional processes are too numerous to discuss in detail here, yet the theoretical curve to which we must be attentive remains: the construction of disabled subjects (Tremain, 2005) are “gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, desires, thoughts, and so on” (Foucault, 1980, p. 97), and exist in a dialectical relationship with the ‘helping professions’, created, in essence, to discipline them under the rubric of modernism. That these professions were defined as new beacons of hope in the reformist agenda does not take away from their need for the existence of deviance for their own survival.

Class differences: the real reason for institutionalization?

Thus far, this chapter has provided a brief tracing of the rise of institutions for the ‘feebleminded’ in North America by examining broad relevant chronological developments, as well as some of the self-sustaining mechanisms embedded within institutionalization via the networks of professionals and supervisors who were intimately involved in their procurement and propagation. I will conclude this chapter with a brief examination of socio-economic factors and their impact on the development of institutions.

While the rapid increase in institutions in the late nineteenth and early twentieth centuries and their ever-widening catchment processes are indisputable phenomena, the macro-sociological and economic forces which undergirded much of their expansion is, according to some, an undertheorized aspect of their development (Radford, 1991; Trent, 1994). To this end, we must interrogate the growth of institutions not only as a historical development which occurred in particular sites during particular periods, influenced by specific and sometimes

unconventional scientific theories, but as a central feature in the “content...[and] matter of production” (Trent, 1994, p. 277). That is, as Trent suggests, analysis must move beyond regarding institutions as sites of incarceration of difference, although they most certainly were, and recognize their position as fixtures in the capitalist economy, as sites of containment for the unproductive, and as geo-political sites which supported the overall functioning of capitalism. In a system based on “production [and] profit” (ibid), institutions were an organizing feature which facilitated the emergent economy, not least because of their role in the internally-sustaining circle of institutional dependence created by the socially constructed need of the ‘feeble-minded’ individual, and the roles of the professionals who cared for them.

Further, institutions were explicit sites of labour exploitation, another requisite feature of a capitalist economy. ‘Feeble-minded’ individuals were seen as unproductive in the larger scheme of productivity, and thus were, in a sense valueless within capitalism. However, the superintendants of some of the earliest institutions began to see residents’ value in filling the labour niches left vacant by others, such as the work needed to maintain the grounds and workings of the institutions themselves (Reaume, 2009; Trent, 1994).⁹ Moreover, people with intellectual disabilities have consistently been regarded as surplus matter. On the scale of human productivity, the capitalist gauge against which people are measured, those who fall short of expectations are an anathema, a dilemma, a problem to be addressed. Institutions, particularly in the early decades of their establishment, provided an opportune deposit site for this surplus population, a population regarded as inessential to the propulsion of the economy. Indeed, capitalism succeeds by its ability to discern the existence of surplus labour, and depositing it where it is most hidden and most convenient.

The link between institutions and the wider web of capitalism brings up additional points. First, during the era of consolidation of the institutionalization movement in North America, up to and including the early years of the twentieth century, the majority of admissions were people of lower socio-economic status (Ferguson, 1994; McLaren, 1990; Trent, 1994). The discursive link between poverty, idiocy, and incompetence, and the corresponding felt need to incarcerate those seen as possessing those features, is a thread which has been persistent throughout institutionalization's history. The supposed "threat" of the 'feeble-minded', which was particularly vehement during the eugenic era, ensured the conflation of various undesirable traits, and poverty was consistently included in the taxonomy. Ferguson (1994) in particular provides a helpful analysis here, as he traces the historical link between the almshouse and specialized institutions. He notes that the custodialism of the American almshouse, including its "grudging, minimal, and... needlessly abusive" (p. 43) model of care, was influential in the establishment of institutions for the 'feeble-minded'. Moreover, he suggests that despite the establishment of new educative institutions, the majority of "poor idiots" (p. 48) remained in almshouses, and that they were largely abandoned (pp. 49-81) within a system which did little to address the economic plight of the majority of 'feeble-minded' people.¹⁰

Second, the dogmatic lack of critical political and economic inquiry during this period is notable. That is, while eugenicists were keen to incarcerate people of lower socio-economic status on the basis of their apparent threat to social and economic stability, these same intellectuals seemed not to question the reasons for this poverty in the first place. While the needs of the new democracies were paramount, the economic instability of certain segments of the population was regarded more as a hindrance than as an area for deeper interrogation and structural change. This might relate to a deeper anxiety, particularly in the United States,

regarding the larger egalitarian goals embedded within its founding narrative. As a response to the monarchical rule from which the new republic was extricating itself, asymmetric economic and power distributions *theoretically* were not meant to exist in nineteenth and twentieth century America. When the difficulty in achieving this ideal began to be realized, a means of dealing with those seen as falling too broadly outside the boundaries of viable production needed to be established, and institutions provided a suitable response. The conflation of disability and poverty lent credence to the segregation of people of differing abilities in order to maintain some semblance of organization in a foundling democracy within which disorder was not welcomed (Rothman, 1971).

However, Scull (1979) offers a note of caution here. He suggests that while it is easy to judge the thinking behind previous generations' mistakes, this is not necessarily a useful analytic tool (p. 62). Rather, Scull suggests, taking our own claims of superiority at face value "blinds [*sic*] us to the transformation of moral boundaries" (p. 63) that our current perspective offers—that is, while we may find the early twentieth century's lack of analysis blatantly uninformed and self-serving, it is, more importantly, indicative of the vast changes in interpretation of both the mechanisms of poverty, and its interconnections with disability, that more recent decades have afforded. What remains consistent, however, with or without the judgement that is wont to appear, is the existence of economic vulnerability in the lives of people with intellectual disability (Trent, 1994, p. 5).

There are, of course, exceptions to this phenomenon. For example, in the mid-nineteenth-century, reform-driven stage of institutionalization, when the promise of educating the feeble-minded and returning them to their home communities was the predominant ideological framework, many admissions came from wealthy families, who were keen to have their children

educated, and had the resources to fund stays at small, private facilities (Trent, 1994, p. 56). And, as forthcoming chapters will illustrate, the phenomenon of admitting those from a higher socio-economic status re-emerged in the latter half of the twentieth century (Radford & Park, 1993a). Indeed, admissions from middle-upper class families have always existed, although the reasoning and the discursive conditions underlying this trend has shifted throughout different time periods. For the most part, however, it is necessary to remain astutely aware of the conflation of feeble-mindedness and socio-economic status, and the impact this configuration has had on the admission practices of government-run institutions.

Conclusion

This chapter has provided a brief overview of the development of institutions in North America in the mid-to-late nineteenth and early twentieth centuries. As such, it provides a map of the gradual ebbs and shifts in discourse, social conditions, and policy decisions which shaped the rise of institutions for the ‘feeble-minded’, and thus affords some perspective of the arc of their development. What has become clear is the extent to which market influences, and the reformist intentions with which they coincided, transformed the ideology concerning people with disabilities from those with which little could be done, to people towards whom the application of some sort of intervention was necessary. That the original, optimistic institutional agenda, as articulated in the educative and production-based rhetoric of the mid-nineteenth century reformers, slid within decades into a custodial and asylum-based model, is a pitiful comment on the commitment of political decision-makers, superintendents, and medical personnel to the actual needs of persons with disabilities. Indeed, it seems that while the intentions of both the reformers and the capitalists seemed well-aligned in their determination to build complex institutions within which to house the ‘feeble-minded’, our current perspective suggests that

perhaps they were essentially incompatible. For, while both groups (and indeed they were, for the most part, one in the same) claimed desire for the transformation of the ‘idiot’ into a productive and healthy being, it appears that in the end, the capitalist edge of the discourse won out, and society embraced the solution that was indeed the most convenient, financially sound, and compatible to capitalist production: long term institutional and custodial care.

While much of the discussion has thus far been theoretical in nature, the next chapter will discuss the more specific growth of the institutions of concern for this project. That is, it will provide a historical and contextual background to the institutions within which the people who were interviewed for this study resided.

Chapter Four: The establishment of institutions for the ‘feeble-minded’ in Ontario

Introduction

The previous three chapters have laid the groundwork for an understanding of the rise of institutions in North America, including broad theoretical elements, contextual factors, and the more prominent features of their development in the nineteenth and earlier twentieth centuries. The first institution established for the ‘feeble-minded’ in Canada was the Orillia Asylum for Idiots in 1876, on the shores of Lake Simcoe.¹ The Orillia asylum became the template for custodial institutional care throughout the country. From a geo-historical perspective, Orillia was the “centrepiece of Ontario’s mental retardation [*sic*] policy” (Simmons, 1982, p. 131), and was “the central point from which mental handicap praxis... diffused throughout Canada” (Radford & Park, 1993a, p. 377). Although it became the benchmark for the large, government-run institutions that were later established in different parts of the province, several decades passed before institutions of a similar size and significance were developed. At the peak of their prominence, however, there were sixteen such institutions for people with intellectual disabilities in Ontario (Williston, 1971)². The notable growth in the number of institutions³, as well as the phenomenal increase in the number of individuals who were housed there, is the principal focus of this chapter.

The discussion which ensues will encapsulate major developments in the establishment of institutions for people with intellectual disabilities in Ontario through four particular points of reflection. First, the rise of institutionalization in Ontario will be examined as a phenomenon which emerged from policy-directed initiatives. Unlike developments in the northeastern United States, which initially embraced, albeit for a brief period, an educative model stemming from idealistic notions of the potential for human improvement, institutions in Ontario were initiated

as a politically-driven response to other “negative considerations” (Simmons, 1982, p. 27) embedded in the broader social fabric. That is, institutions developed, not as a response to the needs of people with disabilities, but as attempts to solve other emergent social problems. Moreover, the policy within which institutional directives were rooted was often subjected to varying interpretations, which had a significant impact on the perceived role and eventual growth of institutions. Second, the trajectory of institutional development in Ontario will be examined as a consequence of the central position that Huronia held as the cornerstone of care for the developmentally disabled in the public and political imagination. That is, much of the reasoning behind the establishment of institutions outside of Huronia’s catchment area stemmed from the need to absorb the human overflow resulting from its endemic overcrowding. Third, I conduct a brief historical tracing of the opening of the fifteen institutions, other than Huronia, which opened prior to the Ontario government’s eventual and long-awaited commitment to deinstitutionalization. And last, institutionalization will be considered in light of the particular subjugation of women during the era of increasing incarceration practices of people with developmental disabilities. This includes a brief consideration of the development of institutionalization as the shadow side of humanitarian impulses which were specific to the early part of the twentieth century.

Institutionalization as ‘negative’ policy

Unlike the idealism which spurred the development of educative institutions for the feeble-minded in the northeastern United States in the mid-nineteenth century, the response in Ontario emerged primarily from policy-driven aspirations (Jongbloed, 2003; Simmons, 1982).⁴ In the United States, the movement which aspired, albeit ultimately unsuccessfully, to establish some kind of rehabilitative or educative environment for the feeble-minded, was grounded in the

educative principles of Seguin and Barr, among others (Ferguson, 1994; Trent, 1994; Tyor & Bell, 1984). In Ontario, however, the predominant model of care for the feeble-minded emerged consistently as one piece of a broader political agenda, with the intention of addressing other emergent social issues, not as steps towards “clearly defined positive policy objectives” (Simmons, 1982, p. 27) for people with intellectual disabilities.

This tendency to develop policy concerning people with intellectual disabilities as a reaction, or indeed, as a solution for other, seemingly more drastic social concerns is one which was repeated throughout the history of institutional development in Ontario. Indeed, Simmons (1982) notes that policy decisions regarding the care and treatment of people with developmental disabilities were based, throughout the end of the nineteenth and the early part of the twentieth century, on “incrementalism” (p. 107), or a pattern which was inclined to “identify situations or ills from which to move *away*, rather than goals *toward* which to move.” (Braybrooke & Lindblom, 1970, p. 102). That is, “even short-term goals [were] defined largely in terms of reducing some observed ill rather than in terms of a known objective of another sort” (ibid). This reactionary style of policy formation meant, essentially, that “the interests of mentally retarded people [sic] were of little account in provincial decision-making” (Simmons, 1982, p. 107). The focus was not the well-being of people identified as having a disability, and whether or not the non-consensual decision to institutionalize was the appropriate response, but rather, energies were diverted to assessments of whether or not, or how well, incarceration of this particular population served other pressing moral and social concerns.

An early example of this is evident from the time of Confederation (1867), when the majority of people identified as being either ‘mad’ or ‘feeble-minded’ were often relegated to the local jail, or to one of the small local asylums for the mad which had developed in a primarily ad-

hoc manner in the mid-nineteenth century (Simmons, 1982). The provincial government's decision to build a separate institution for the feeble-minded, which would eventually become the Orillia Asylum for Idiots, was not necessarily an indication of greater solicitude for the particular needs and concerns of this group of people, but rather was a direct result of the need to "alleviate pressure for space on local jails and the main asylums, to cut costs, and to improve the therapeutic climate for the curable mentally ill" (ibid, p. 27). During this time period, that is, the latter half of the nineteenth century, when influential decisions were being formulated—essentially, the establishment of the custodial institution as the primary response to intellectual disability—there was no one individual or group who took up the cause of feeble-minded people, nor put their considerations at the same political level as alleviating space in local jails or minimizing costs of maintaining already-established asylums. This tendency to position the economic concerns of the province, or of the institution, above that of the people housed within, is a pattern which would repeat itself well into the twentieth century (Radford, 1991; Radford & Park, 2003, 1993a, 1993b; Simmons, 1982).

The work of Helen MacMurchy is another example of the use of the institution as a means to assuage consternation regarding other grave social concerns. As Inspector of the Feeble-minded in Ontario from 1905 until 1920 (although she was only officially named to the post in 1915), she carried a considerable amount of influence in the placement of children considered unfit to live outside the confines of the institution. With incredible fervour, MacMurchy strove to identify as many 'feeble-minded' children as possible and advocated strongly for their removal from the family home and placement in the institution at Orillia. While her drive to establish auxiliary classes within the education system for feeble-minded children could be regarded as an attempt to provide them with a chance to receive an education, it is also

clear that she saw these classes as opportunities through which she could identify those whom she felt were more fit for “permanent custodial care” (MacMurchy, 1907, as cited in Simmons, p. 78). The onset of mandatory and free public education around the turn of the century (McLaren, 1990; Trent, 1994), made available a much larger pool of children from which MacMurchy could draw and ultimately send on to permanent institutionalization. Institutions were needed, according to her statistics, to meet the ever-increasing number of deviant and backward children. Accordingly, MacMurchy’s work, which has since been shown to be pathetically unsubstantiated and exaggerated (McLaren, 1990; Simmons, 1982), reinforced the tendency to use policy to create makeshift solutions for what were considered serious social concerns at the time—in this case, the intermingling of ‘feebleminded’ and ‘normal’ children in the regular school system—which ultimately had profound and devastating implications for people with intellectual disabilities.

Using institutionalization as a means to resolve the apparent social and economic crises which seemed to threaten the late nineteenth century social fabric, besides demonstrating complete disregard for the well-being of the people implicated, also resulted in virtually no movement in policy which concerned people with intellectual disabilities during the late nineteenth and early twentieth centuries in Ontario. While this could be interpreted as a time of reprieve, as no further damaging policies were officially instigated, it also suggests an overriding attitude of negligence, and a climate within which to make better the living conditions of people with disabilities was deemed neither prudent nor necessary. Decisions regarding disabled people were made only when they served the “negative considerations” to which Simmons refers, when this would have meant a resolution of the anxiety concerning other social issues, such as maintaining jail populations at reasonable levels, or containing the threat of the perpetuation of

the ‘feeble-minded’ by insisting on custodial care for women of childbearing age (McLaren, 1994; Simmons, 1982). Once the custodial model of care had been established, primarily through the auspices of the Orillia Asylum, superintendents and decision-makers did not see a need to alter it, nor was there any political will to do so, as it served numerous social functions, and several decades passed before there was any noticeable positive change in the approach and attitude towards care for people with intellectual disabilities in Ontario.

Moreover, by the turn of the twentieth century, institutions began to be envisioned as sites of economic self-sustainment. A. H. Beaton and J. P. Downey, the two superintendents at Orillia during this era (from 1877-1910 and 1910-1926, respectively)⁵, realized that a well-run institution could, with a large pool of capable inmates, feed and clothe itself. Indeed, Downey’s central preoccupation “seemed to be less whether prospective inmates were really mentally retarded [sic] and more whether or not they were good workers” (Simmons, 1982, p. 104). Downey imagined a ‘corporate system’ (ibid, p. 105) within which various institutions in the province could support each other by meeting each other’s material needs around such items as clothing, shoes, and produce. Beaton, Downey’s predecessor, had begun to consider Orillia a closed system, that is, to minimize, or even eliminate the number of discharges from the institution in order to maintain a reliable and essentially, imprisoned, workforce. This drive to equip the inmate body of the institution with as many capable workers as possible in order to potentiate its productivity was a continuation of a philosophical tenet, long embedded within the institutional history of the province, to keep their running costs as low as possible. Indeed, the “goal of efficiency became paramount” (ibid, p. 83), and superintendents prided, perhaps even competed among themselves, on their ability to maintain the institution as cheaply as possible. This practice of using patient labour and framing it within the “rhetoric of moral treatment”

(Reaume, 2006, p. 73) while failing to disclose its pivotal role in meeting the institutions' "internal economy needs" (ibid) and reducing expenditures from the public purse, parallels the use of patient labour in all manner of asylums throughout nineteenth and early twentieth century Ontario (Reaume, 2006, 2000). Further, while outward appearances of productivity gave the impression of well-run, organized establishments that provided meaningful 'employment' to hundreds of individuals, this was also part of the outward maintenance of a particular reputation, entrenched within Orillia's history, of being able to function with far less money than other institutions, including those in the northeastern United States (Radford & Park, 1993b; Simmons, 1982). While this might have been considered an accomplishment, and perhaps even justification within political circles for the continuation of Orillia, this also meant that there was no great hurry to implement policy which would facilitate opportunities for people with intellectual disabilities outside of institutional, custodial care. Accordingly, the incentive to maintain a high number of capable, working residents within its walls became another contributing factor to the consistent increase in the population at Orillia.

Moreover, in the approximately one hundred-year span between the establishment of the Orillia Asylum in 1876 until the beginnings of the deinstitutionalization movement in the 1970s, and particularly in the earliest decades of Orillia's existence, besides the lack of progress in existing policy, there were also divergences in its interpretation, which resulted in consistent and significant increases in the numbers of people being admitted to Orillia. While Orillia was established specifically as an "Asylum for Idiots and Imbeciles", municipalities frequently relegated an array of socially undesirable and demanding individuals, such as the elderly and people of low socio-economic means, to the care of the province via the local jail. Once their position within the trusteeship of the province was secured, it was bureaucratically simpler for

inmates to be consigned to the provincially-run institution for the feeble-minded (Radford, 1991; Simmons, 1982). Further, medical superintendents who were initially involved in these decisions continued to interpret the function of the asylum in much the same way as the earliest hospitals, that is, to provide a social welfare function, wherein all who came to live at the asylum, whether for ‘feeble-mindedness’ or for a host of other prevalent social problems such as poverty or illegitimate pregnancy, were not refused entry (Simmons, 1982, p. 48). Thus, while the institution at Orillia had originally been designed for a limited population of ‘feeble-minded’ people whose possibilities for care within the community were negligible, it began to be used, rather, to “fulfil a social welfare function which was... unlimited in scope and clientele” (ibid).

Thus, variant interpretations around policy, as well as its ongoing emergence as a response to alleviate other, more seemingly pressing moral concerns, meant that there was virtually no positive policy formation regarding the concerns of people with intellectual disabilities for almost a century in Ontario, nor was there any critical response from the public. Indeed, the entire process seemed stuck in a custodial model against which virtually no critique was directed. While people were often directed to the Orillia Asylum as a last resort, there was, in effect, no questioning from either politicians or the general public that there might be preferred alternatives. Accordingly, with some fluctuations, the residential population at the Orillia Asylum continued to climb (Radford & Park, 2003, 1993b; Simmons, 1982). Whereas in 1880, four years after its opening, there were one hundred fifty-six residents at Orillia, by the turn of the century, there were four times as many residents, six hundred fifty-four, and by the 1920s, there were over one thousand (Radford & Park, 2003, 1993b; Simmons, 1982, pp. 314/315—see Figure 1). Moreover, the combination of political indifference and reluctance to implement any positive change, and Orillia’s historical position as the centrepiece of custodial care, meant that

Year	Number of residents
1876	59*
1881	159*
1886	218*
1891	420*
1896	605*
1901	652*
1906	761*
1911	809*
1916	828*
1921	1,056*
1926	1,321*
1931	1,422*
1936	1,847*
1941	2,010*
1960	2,800**
1972	1,868***
1977	1,243***

Figure 1: Number of residents at the 'Orillia Asylum for Idiots' / Huronia, 1876-1977

Sources:

*Simmons, H. G. (1982). *From Asylum to Welfare*. Downsview, ON: NIMR, pp. 314-315.

***_____. (ibid), p. 199.

**Williston, W. (1971). *Present arrangements for the care and supervision of mentally retarded persons in Ontario*, p. 29. Toronto: The Queen's Press.

Note: As Simmons (1982) notes, while the figures suggest that the total number of institutionalized individuals began to drop after 1965, these numbers may be misleading. At that time, residents of Schedule 1 facilities began to be transferred to the *Homes for Special Care* programme, and thus were not included in the year-end figures, yet were “by no means deinstitutionalized” (p. 313). Moreover, some residents with intellectual disabilities who lived in psychiatric institutions were also not included in these figures. Thus, it is “extremely difficult to pinpoint an exact date when the decline in the institutional population began” (ibid).

when other institutions did eventually begin to develop in Ontario, the impetus was not necessarily to move forward in a positive way towards people with intellectual disabilities and their families who were underserved in the community, but rather to absorb the overflow from Orillia's walls.

The alleviation of Orillia's excess

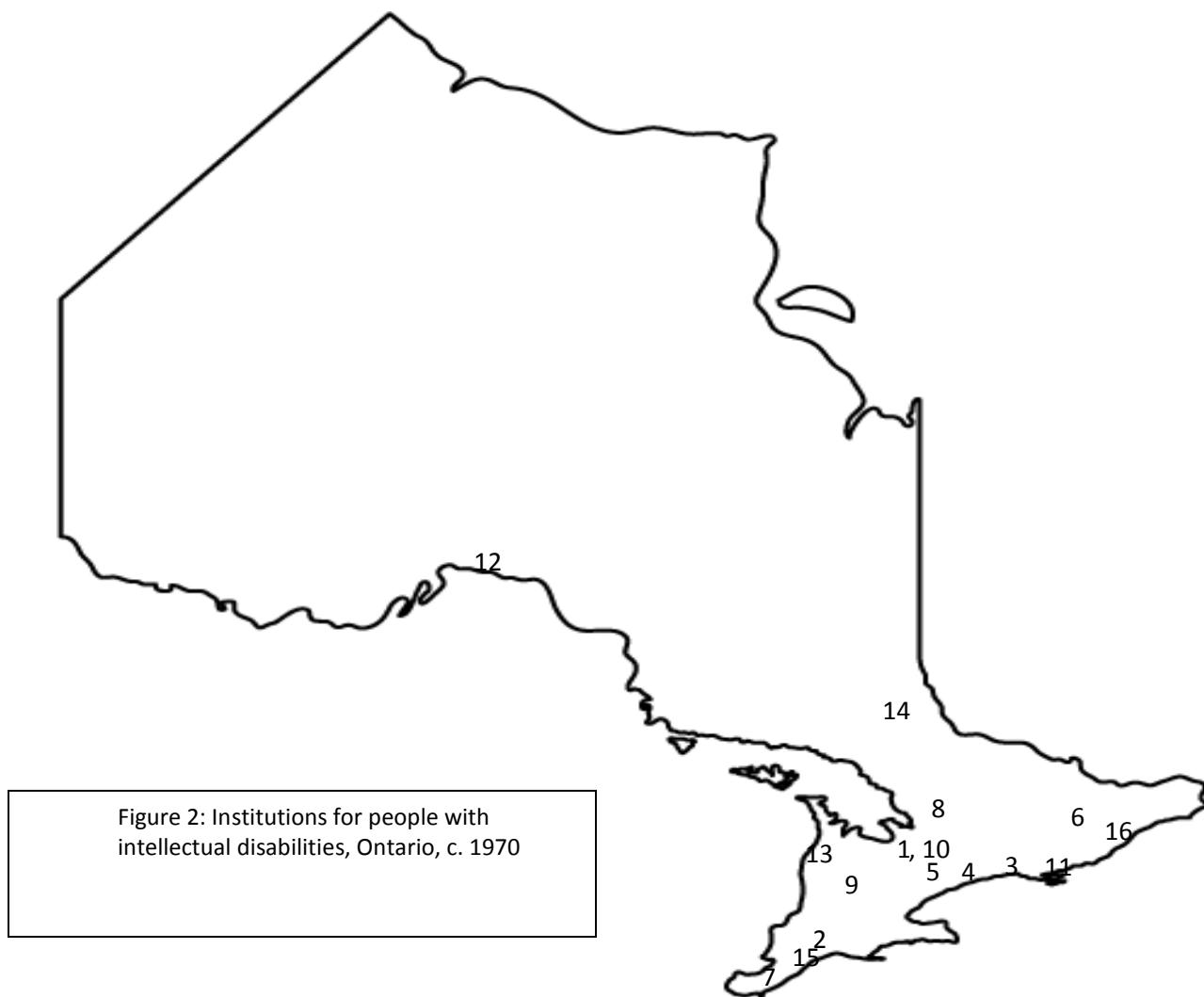
As mentioned, the asylum at Orillia was the centrepiece of the custodial model of care which was firmly entrenched within Ontario policy towards people with intellectual disabilities in the first half of the twentieth century. The trajectory of development of the other institutions in the province suggests that they were primarily a response to Orillia's inability to house the large numbers of people whose guardians were appealing for their admission. Two massive institutions, Smiths Falls and Cedar Springs, were opened in 1951 and 1961 respectively, and the provincial governments at the time were clear that these facilities were intended to alleviate the constant pressure on Orillia to admit more residents.⁶ Indeed, although built almost one century later, they were constructed with the same intention as that which had directed the original construction at Orillia, that is, to house large numbers of people in an isolated and custodial setting, with no explicit plan towards their release or re-integration into the community. Smiths Falls and Cedar Springs were located in distinctly different regions, giving the impression of a broad triangle which covered roughly the majority of the most densely populated portion of the province. Their placement was judicious, and it is clear that their construction was primarily a way to increase the number of 'beds' available to the intellectually disabled, the number of which at Orillia seemed insufficient to meet the incessant demand for admission (Radford & Park, 2003, 1993b; Simmons, 1982, p. 162). Moreover, on close examination, it becomes clear that the

smaller institutions which developed throughout the 1960s and 1970s (see Table 1), in a scattering of rural and small-town locations throughout the province, were more or less also considered satellites of the original stronghold at Orillia (Radford & Park, 2003). Policy decisions seemed to flow from Orillia's historical position: politicians were compelled to make decisions when Orillia became overcrowded, and for the most part, they responded by building more institutions as a remedial measure to stem its overflow.

Thus, despite increasing noise throughout the 1960s and 70s from parent groups for the government to consider alternate methods of care (Radford & Park, 2003; Simmons, 1982; Williston, 1971), the government chose instead to react to the situation at Orillia, which was seen primarily as an issue of insufficient beds, by building more 'housing' along similar geographic and philosophical criteria. Accordingly, several smaller institutions were established on the outskirts of small towns, such as Gravenhurst (1963), Palmerston (1965), Picton (1970), and Goderich (1976) (see Figure 2). Notable also is the manner in which the government conducted this expansion. Throughout this period, a number of former army bases and abandoned 'asylums for the insane' came under the control of the provincial Ministry of Health and were converted into institutions for the intellectually disabled. Thus, far from moving in a direction of positive policy formation for people with intellectual disabilities and their families, the government chose instead to allow Orillia to maintain its position as the model of care, including its location and design, and, through lack of political will to alter a system which already seemed to be working, built numerous other custodial asylums with the primary purpose of absorbing the flow of people unable to be held at Orillia.

Table 1: Schedule 1 Institutions for people with intellectual disabilities, Ontario					
<u>Original Name of Institution</u>	<u>Name at closing</u>	<u>Location</u>	<u>Year opened</u>	<u>Year closed</u>	<u>Notes</u>
Orillia Asylum for Idiots / Ontario Hospital School, Orillia	Huronian Regional Centre	Orillia	1876	2009	First and longest-standing facility for ppl with intellectual dis in Ontario. Capacity: approx. 1200; peak pop'n: approx. 1900.
Oxford Mental Health Centre	Oxford Regional Centre	Woodstock	1905	1997	Originally intended for ppl with epilepsy and TB from Orillia; later functioned as 'mental retardation' unit in psychiatric hospital; peak pop'n approx. 320
Ontario Hospital, Cobourg	D'Arcy Place	Cobourg	1920	1996	Originally opened as an institution for 'feeble-minded' women; peak pop'n: approx. 300
Ontario Hospital, Whitby	Durham Centre	Whitby	1950s	1987	Originally a 'mental retardation' unit at Whitby Psychiatric Hospital.
Ontario Hospital, Aurora	Pine Ridge Centre	Aurora	1950	1984/5	Original bldg was a residential school for boys; opened to relieve overcrowding at Orillia; peak pop'n approx. 200
Eastern Hospital for Defectives / Ontario Hospital School, Smiths Falls	Rideau Regional Centre	Smiths Falls	1951	2009	Capacity: 2,400; peak pop'n approx: 2,000; huge institution; main corridor over 500m long.
Ontario Hospital School for Retarded Children at Cedar Springs	Southwestern Regional Centre	Blenheim (Chatham- Kent)	1961	2008	Third in the triad of large institutions (incl. Huronia and Rideau Regional Centres). Intended capacity: 2,000; peak pop'n approx. 1,000
Muskoka Centre	Muskoka Centre	Gravenhurst	1963	1994	Original bldgs a TB sanatorium; opened as a satellite of Ontario Hospital School, Orillia; peak pop'n approx. 400

Midwestern Regional Children's Centre	Midwestern Regional Centre	Palmerston	1965	1998	Originally a residence for children; later admitted adults; peak pop'n: approx. 220
Adult Occupational Centre	Adult Occupational Centre	Edgar	1966	1999	Bldgs originally RCAF radar station; Built to accommodate Orillia overflow; adult occupational training facility; peak pop'n approx. 250
Prince Edward Heights Hospital School for the Mentally Retarded	Prince Edward Heights Adult Occupation Centre	Picton	1970	1999	Bldgs originally a Canadian Forces base; peak pop'n approx. 60
Northwestern Regional Centre		Thunder Bay	1974*	1994	Opened as a 'mental retardation unit' in Lakehead Psychiatric Hospital; peak pop'n approx. 300
Ontario Hospital, Goderich	Bluewater Centre	Goderich	1976	1984/5	Bldgs have been converted to a youth detention centre.
Nipissing Regional Centre	Nipissing Regional Centre	North Bay	1975	1977/8	Began as 'mental retardation' unit in North Bay Psychiatric Hospital
St. Thomas Adult Rehabilitation and Training Centre (START)	START	St. Thomas	1975	1984/5	Began as 'mental retardation' unit in St. Thomas Psychiatric Centre
St. Lawrence Regional Centre	St. Lawrence Regional Centre	Brockville	1975	1984/5	Extension of Brockville Psychiatric Centre



1. Huronia Regional Centre, Orillia (1876)
2. Oxford Regional Centre, Woodstock (1905)
3. D'Arcy Place, Cobourg (1920)
4. Durham Centre, Whitby (1950s)
5. Pine Ridge Centre, Aurora (1950)
6. Rideau Regional Centre, Smiths Falls (1951)
7. Southwestern Regional Centre, Blenheim (1961)
8. Muskoka Centre, Gravenhurst (1963)
9. Midwestern Regional Centre, Palmerston (1965)
10. Adult Occupation Centre, Edgar (1966)
11. Prince Edward Heights, Picton (1970)
12. Northwestern Regional Centre, Thunder Bay (1974)
13. Bluewater Centre, Goderich (1976)
14. Nipissing Regional Centre, North Bay (1975).
15. St. Thomas Adult Rehab and Training Centre, St. Thomas (1975)
16. St Lawrence, Brockville (1975)

Parent groups, education, and ongoing custodial care

After several decades of virtually no movement in the institutional system in Ontario, change gradually began to be felt in the middle of the twentieth century. One of the key developments in the eventual abandonment of the custodial system in Ontario was the beginning of the parents' movement. After the Second World War, there was a generalized public sense of humanitarianism and an awareness of the necessity of ensuring human rights to all members of the population. The brutal destruction of the war, as well as an awareness of the atrocities that had been committed in the name of philosophical allegiance, resulted in a gradual reframing of attitudes towards marginalized groups, and "for the first time, large numbers of people began to argue that mentally retarded people should have the same rights and privileges as other members of society" (Simmons, 1982, p. 158). Accordingly, parents of children with intellectual disabilities began to demand equal services and opportunities for their children, not necessarily in the form of charitable acts, although this discourse had a definite place in post-WWII North American culture, but "as a right owed to [them]... as full citizens of the post-war era" (ibid).

The primary point of intersection between parent groups and the government was through the education system. Parents who had decided not to institutionalize their children began organizing their own nursery and community schools, and began advocating for funding from the provincial government with the argument that children with intellectual disabilities "deserved the same social benefits as every other citizen" (Simmons, 1982, p. 158). While there were numerous challenges along the way, momentum began to swing in the parents' favour, such that between 1962 and 1968, there was a steady increase in the amount of financial government support for schools for children with intellectual disabilities. Although enormous challenges remained in regards to inclusion within the school system, accessibility, and integrated

classrooms versus segregated schools, in 1968, full funding for schools for disabled children was granted by the provincial government, an enormous achievement when considered within the consistently oppressive context of the previous half a century.

Despite these gains, however, the number of people who remained incarcerated in provincial institutions continued to grow (Radford & Park, 2003, 1993a; Simmons, 1982—see Figure 3). Indeed, in spite of increasing awareness of the rights of disabled people to participate meaningfully in all aspects of society, including the right to stay home with one's family and attend school, continuous pressure to admit more people to custodial care, and to build more institutional spaces, remained (*ibid*). Perhaps surprising to current understandings, much of this pressure came from parents of disabled children themselves. Despite the growing trend to keep one's child at home, in light of the ubiquitous lack of support for children with disabilities and their families, as well as phenomenal pressure to admit children to provincially-run institutions, hundreds of families continued to assume that institutionalization was the preferable option (Radford & Park, 2003, 1993a; Trent, 1994). Indeed, the lack of movement within the government to invest in anything other than new institutional spaces, or improvements in existing ones (Simmons, 1982, p. 168) meant that many families who found themselves in trying circumstances felt that there were no options besides long-term custodial care. Moreover, Strong-Boag (2007) notes that during this era, families deemed 'at risk' were frequently subjected to coercion by health and welfare authorities to place their children in institutions because of the family's seeming inability to care adequately for the child.

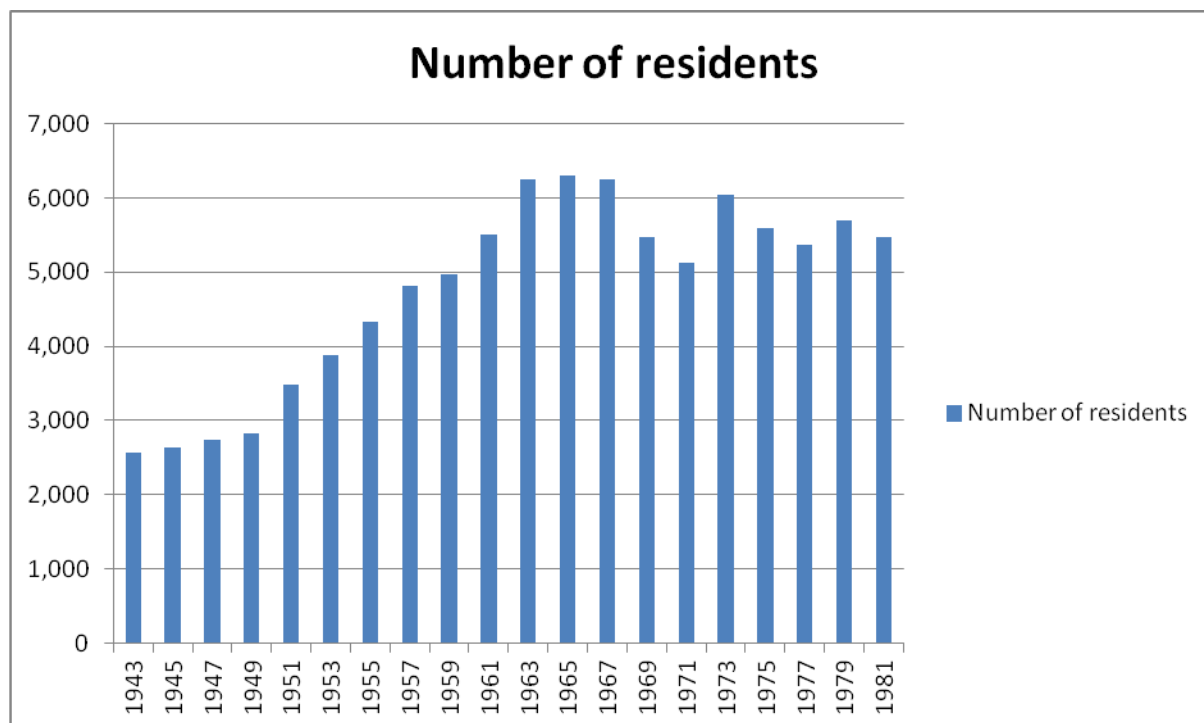


Figure 3: Number of residents at all Schedule One Facilities, 1943-1981

Please refer to the note at Figure 1.

The pressure to increase institutional capacity continued even in light of a report presented by Williston in 1971, which advocated strongly for the development of community resources for people with disabilities and their families, and the closure of all the large, government-funded institutions in the province.¹ While Williston’s report recommended that “the large hospital institutions for the mentally retarded be phased down as quickly as is feasible” (Williston, 1971, p. 65), thirty-eight years passed before the last large, provincially-run institution closed in 2009. Indeed, even after Williston’s report was tabled, five more institutional settings were opened in the province.² There are two principal reasons for the intransigently slow pace of institutional closure in Ontario.

First, the ideology of the governing Conservative/Progressive Conservative (C/PC) party, which had held the majority of power in Ontario since 1905³, was in contradiction to any services for people with intellectual disabilities that fell outside the realm of custodial institutional care. The Conservatives/Progressive Conservatives adhered to a residual model of care (Guest, 1985; Simmons, 1982), which suggests that “social welfare institutions should come into play only when the normal structure of supply, the family and market break down” (Wilensky & Lebaux, 1965, p. 138 ff, cited in Simmons, p. 169). That is, if, after all avenues were attempted and all resources were depleted, a family was deemed unable (whether by their own opinion or that of the state), to support a family member with a disability, the government would then provide the means with which to support him or her, under their own terms—in this case, complete institutionalization. Moreover, C/PC ideology has historically been in alignment with traditional disciplines such as medicine and education. Increases in funding to community services for people with disabilities was, in the eyes of the government, a “social welfare function” (Simmons, 1982, p. 171), one which did not align with their main philosophical tenets, and presented a role with which they were “not prepared to engage” (ibid).

For these reasons, the C/PC government, which held the majority of power from the time of the initial solidification of custodial care in Ontario through the first workings of the deinstitutionalization movement, was generally unwilling to commit, financially or otherwise, to programmes which might have made it easier for people to support family members with intellectual disabilities to live in the community. Further, Simmons (1982) suggests that the residual model to which the government adhered is one of the reasons why the government also did not feel committed to the provision of optimal care to institutionalized individuals, as this model assumes that “the obligation to provide care is not unlimited” (p. 169). Moreover, a

residual model assumes that with the provision of lesser care, people are more inclined to aspire towards taking responsibility for their own situation, and will attempt to rectify it via their own means. Within this model, therefore, minimalist care is seen to motivate individuals to alleviate the dire circumstances within which they may find themselves. The government did not seem concerned with the inconsistency in this ideology when it came to intellectually disabled people, that is, that their incarceration and release were completely at the hands of government officials, and that the ability to ‘compete’ for resources, as the residual model dictates, would have fallen solely on the family, thus negating the theoretical notions of autonomy and self-sufficiency upon which this model hinges. Moreover, it is interesting to note that when, under mounting pressure to put Williston’s recommendations into action, the government began to take steps towards community care for people with intellectual disabilities, officials were careful to use language that included the ‘family’. While at first appearance this may seem like a concerted effort to work in alignment with families in order to best support people in the community, a more critical interpretation suggests that this was, rather, a thinly veiled statement by the government that families would be expected to burden a good deal of the responsibility for the care of people in the community, and that government would play as minimal a role as possible (Simmons, 1982, p. 175). As Simmons has pointed out, at this time, the government was not “justifying public education or health care in terms of preserving the family” (p. 175), but felt quite comfortable to appeal for their assistance when it came to people with intellectual disabilities.

The second principal reason for the government’s long adherence to the institutional model is more political in nature. Records indicate that the primary method of admission for many persons with disabilities was through pressure to one’s local Member of Provincial Parliament (MPP) (Simmons, 1982, p. 165). MPPs had good reason to try and gain admission for

the constituent families who were appealing to have their children placed in an institution. Members seeking re-election were happy to oblige requests whenever possible; the volume of requests, moreover, gave opposition members fodder to challenge the governing party in its intransigence regarding the development of policy, or simply in providing more institutional space (ibid, p. 162). Moreover, the locations of institutions were also political in nature. The Conservative / Progressive Conservative party knew that their largest constituent base lived in rural areas (Simmons, p. 173); hence, to locate institutions in rural sites or small towns ensured an economic boom in that area, primarily through the employment of local people as staff. Further, to oblige communities in their preference for institutions as opposed to community care (that is, in which people with intellectual disabilities were unseen as opposed to seen) were opportunities to build favourable popular opinion, and future political support.

For the reasons outlined above, the building of more institutional spaces for people with intellectual disabilities continued throughout most of the 1960s and into the 1970s (see Table 1). As discussed, the ‘satellite’ nature of the newer, albeit smaller institutions, suggest that they were primarily developed in response to overcrowding at Huronia. That this growth continued in spite of growing pressure for the government to close down the large institutions, and to provide more support for community care is evidence of a growing tension in disability policy in Ontario. This tension encountered a significant shift, however, when the jurisdiction for services for people with intellectual disabilities was transferred from the Ministry of Health to the newly-formed Ministry of Community and Social Services in 1974. The transfer of care for people from the auspices of health brought in a new era for people with intellectual disabilities in the province of Ontario, for, with a lessening of the authority of the medical profession, an influx of expertise

from other professional disciplines, and an increasing awareness of the inherent right of all people to live where they choose, the prerequisites for institutional closure were in place.

While the preceding paragraphs have outlined the historical development of institutions for people with intellectual disabilities in Ontario primarily from a policy-oriented perspective, I will conclude this chapter by looking briefly at a particular social concern which emerges as a consistent feature in the literature concerning the rise and use of institutions for the ‘feeble-minded’: the historical treatment of ‘feeble-minded’ women, and indeed, the subjugated role of women in society in general, and its contribution to the ongoing institutionalization of people with intellectual disabilities. This is a concern which links the earliest origins of the institutionalization movement to decision-making practices regarding the placement of family members with intellectual disabilities in institutions in the mid-twentieth century, the latter being a topic with which this project is concerned, and which will be dealt with in the next chapter.

The subjugation of women and the institutionalized population

While the increasing embrace of the custodial model of care for the intellectually disabled can be attributed to the political factors outlined above and in preceding chapters, the position of women in early twentieth-century Ontario also played a particular and significant role. The position of women at the turn of the twentieth century, while at the cusp of significant changes in regards to their role and acceptance within patriarchal society, remained firmly embedded within the domestic realm (Lamp, 2006). Women’s role as bearers of future generations remained entrenched as a social and indeed, political priority (McLaren, 1990). Moreover, as scholars have indicated (Lamp, 2006; Rafter, 2004; Trent, 1994) the cultural discourse of ensuring the births of healthy, ‘non-idiot’ children gained steady momentum during this era, a time increasingly coloured by the eugenic hyperbole being presented by social

reformers. While this rhetoric was often presented as a concern for the future well-being of children and their potential for success in an increasingly competitive world, in essence, the primary point of intervention was through the reproductive lives of women (Rafter, 2004). Social reformers made clear that if the flow of ‘idiot’ and ‘imbecilic’ children were stemmed at the source, that is, were policies put in place to ensure the prevention of their births in the first place, a myriad of social ills might be prevented (McLaren, 1990; Radford, 1991). The Ontario government’s decision to segregate women seen as a threat to the integrity of the race plowed ahead, despite the inaccurate and sometimes non-existent data regarding the rates of children being born in the province to women identified as ‘feeble-minded’ or otherwise. The segregation of women was the chosen eugenic tool in Ontario (Radford, 1991), and the symbiotic relationship between public fears of race pollution and the convenience of the institution proved serendipitous for successive provincial governments.

When examined, however, the segregation of ‘feeble-minded’ women was more complicated than the simple ideology concerned with preventing them from producing children. The unfounded but popular assumption that feeble-mindedness was connected to one’s position within the unemployed or lower working classes reinforced the predominantly middle-upper class reformist ideology which included clear distinctions between oneself and those seen as different (Lamp, 2006; Radford, 1991; Simmons, 1982). Moreover, these distinctions had much to do with the “reformers’ distaste for, and condemnation of those whose sexual mores were different from their own” (Simmons, 1982, p. 70). Feeble-mindedness was associated with a particular social understanding which included presumptions of promiscuity among ‘feeble-minded’ women, and the resultant need to enforce their segregation from mainstream society. The discursive construction of ‘feeble-minded’ women began to consist of a number of

overlapping and widely disapproved traits whose common points of intersection frequently had to do with sexual practices. Thus, by World War I, feeble-mindedness was linked to “prostitution, illegitimacy, and venereal disease” (ibid, p. 95). The public call to eliminate the ‘evils’ of communicable diseases and the practice of prostitution spilled without resistance into a resounding discourse to prevent ‘feeble-minded’ women from bearing children by separating them from the rest of the population. Indeed, social reformers exhibited “strident moral condemnation of illegitimacy among feeble-minded women [and used this] as proof of the necessity of custodial care” (ibid, p. 70). Thus, while custodial practices had distressing consequences on both men and women, there is no doubt that an overriding concern regarding the propagation of increasing numbers of ‘feeble-minded’ children had a particular and devastating impact on women.

These concerns were frequently couched as humanitarian in nature. As we have seen in previous chapters, and as we will continue to see in subsequent discussions regarding institutional care in Ontario, the use of the discursive tools of humanitarianism and concern for the common good were frequently employed in order to justify discriminatory practices exhibited against intellectually disabled people. Helen MacMurchy’s call for segregated school classes, her subsequent rhetoric regarding the need to separate ‘feeble-minded’ women of child-bearing age from the rest of the population in order to protect the future of the race, and the reformists’ general message regarding the need to protect ‘feeble-minded’ people from the “vicissitudes and cruelties of the outside world” (Simmons, 1982, p. 66), while presented as compassionate directives, can be seen as tools of oppression against those who fell outside intellectual and moral norms. Thus, while the early rhetoric of institutionalization included a discourse of concern about the habits and practices of women, our current vantage point allows us to understand it as a

“bizarre combination of humanitarianism, prudery, vengeance, [and] desire for social control” (ibid, p. 67).

Moreover, by the end of World War I, directives regarding segregation and custodial care were being framed as public health concerns, particularly in regards to women and children. An increasingly sophisticated public, and one increasingly well versed in science’s ability to lessen or eradicate the effects of disease, might be even more inclined to accept the segregation of women to protect the health of the general population, as well as for the moral and class distinctions that were already in place. Accordingly, ongoing institutionalization as a tool of segregation was justified on several fronts: to prevent reproduction in ‘feeble-minded’ women and thus protect the future of the race, and as a public health measure to protect large numbers of the general population from the vices of prostitution and promiscuity.

An awareness of the subjugation of women is relevant as we move forward into an analysis of the decision-making processes of families who placed a family member in an institution. For while there appears to be differences between the discourses surrounding women during the era of the beginning of institutionalization, and those which existed after WW II, there remains a common thread of women’s incapacity, whether it be the inability to care for oneself in a manner appropriate to social and cultural norms (in the case of the early twentieth century ‘feeble-minded’ women), or the inability to care adequately for a child with a disability (as was the case with many mothers who were raising children in the 1950s and 60s). Thus, a discursive undercurrent of incapacity, including the need for society to both protect itself *from* the dangers of women, and to provide protection *for* women, was a consistent feature in the landscape of institutionalization processes in twentieth century Ontario (de la Cour, 2013). The manifestation

of this discourse in the lives of families, and the impact that this had on the lives of people with intellectual disabilities, is one of the issues which will be discussed in the next chapter.

Conclusion

This chapter has discussed the specific development of institutions for people with intellectual disabilities in Ontario throughout the twentieth century. In particular, it has examined their emergence as a political response to other identified social and moral concerns, and as the outcome of the workings of ‘negative’ policy. Ontario’s historic lack of positive policy development in the area of intellectual disability, and an entrenched political belief system which saw little change during the first eighty years of the twentieth century, resulted in the entrenchment of the custodial model of care and the development of increasing numbers of institutions for people with intellectual disabilities, despite growing calls for their closure.

The next chapter, as an introduction to the discussion of the findings in this study, will examine some of the specific social and cultural conditions regarding family decisions to place their children in institutional care after World War II in Ontario.

Chapter Five: Families, children with disabilities and the pressures of cold war conformity¹

Introduction

The previous four chapters have provided historical and political background to the development of institutions for people with intellectual disabilities and bring us to the specific time period with which this study is concerned. This chapter will deal with the social, cultural and political conditions of post World War II Ontario that contributed to family decisions to place a child with intellectual disabilities in an institution. While the findings of the empirical research conducted for this study will contribute to reflections in this area, some of the more prominent features of family life, and the social and political trends surrounding it, will be examined here as a precursor to the more particular details of discernment with which each family had to contend. Before addressing these particular socio-political conditions, however, it is important to note that although hundreds of families decided to place a family member with a disability in an institution, and it is these decisions and their implications which are the focus of this study, there were many more families who did not take this route and chose to keep their family member with a disability at home. Indeed, both Ferguson (1994) and Simmons (1982) suggest that not more than ten percent of the population of people with intellectual disabilities were actually residing in institutions at any given time, and census figures would concur with this estimate². Thus, while I seek to address the implications of familial decisions to institutionalize in our more recent history, I do so with an acknowledgment of the ongoing research need, which exists beyond the parameters of this study, to examine more thoroughly the subjective experiences of families who chose differently.

At the outset, it is essential to place contextual and definitional boundaries around the time period of concern, from the end of the Second World War to the 1980s, when the

deinstitutionalization movement had established itself as a valid social concern and had begun to make consistent progress in social and political circles. The decades immediately following the end of World War II in North America, as elsewhere, have categorically been summarized as the Cold War, an approximately forty-year span frequently defined as the heated political, rhetorical, and sometimes threatening contest of wills between the United States and the Soviet Union, both representative of new forms of imperialism as exemplified by capitalism and communism respectively (Cavell, 2004; Whitaker & Marcuse, 1994). From this perspective, the Cold War can be crudely understood as the political wrangling between two ‘superpowers’ seeking dominance on the international stage in an era marked by the possibility of annihilation through atomic warfare, and all of the associated rhetoric that tension engendered. Both powers were consumed with the drive to establish itself as the better-equipped, and hence better-prepared state in the event of diplomatic breakdown and the outbreak of war. Entrenched underneath this immense militaristic manoeuvring, however, were particular cold war discourses—in particular, the notion of ‘containment’ (Cavell, 2004; Iacovetta, 2006; May, 2008) —which had implications far beyond war planning rooms, and were manifested in more intimate social and cultural practices embedded in the family and the domestic rituals of everyday life. From a North American perspective, the principle ideological thrust during this era was the containment of communism which, at the time, was seen as the principle threat to the consumer-based, post-war idealized lifestyle towards which North Americans were encouraged to aspire (May, 2008; Brookfield, 2012; Runté & Mills, 2006). Beyond this core argument, however, discursive constructions of the Cold War included the pervasive threat of the ‘other’ (Cavell, 2004), as well as the responsibilities of individual citizens to contain this ‘other’ both linguistically and materially (Iacovetta, 2004; Kinsman, 2004; May, 2008; Whitaker, 2004; Whitaker & Marcuse,

1994). Moreover, Cold War discourse was profoundly influential in the discursive constructions of gender, work, sexuality and the family, each of which served particular social and political purposes. This era is marked, therefore, by the intimate exchange between the discursive constructions of men, women, and the family, and the militaristic framing of social and cultural life.

Thus, when considering the family and factors which contributed to decision-making within families, this time period cannot be regarded solely as the ongoing, albeit essentially static tension between two superpowers (Whitaker, 2004). Rather, it must be seen as a time during which social and political discourse had profound influence on all aspects of public and private life, including family life, and the treatment of society's more vulnerable members. The purpose of this chapter, therefore, is to engage the larger discourses of this era in order to better understand the processes within smaller social institutions such as the family, in particular, processes of discernment with which families would have grappled around the care, role and place of belonging of family members with an intellectual disability.

Before proceeding any further, however, an important geographic and political distinction must be made. The Cold War is generally understood as the particular military and political tension that existed between the United States and the Soviet Union in the decades immediately following the Second World War, and has, therefore, primarily been examined in relation to these two superpowers (Cavell, 2004; May, 2008; Whitaker, 2004). Scholars have noted that the implications of the Cold War in terms of domestic and foreign policy, as well as blatant militarization, were keenly felt in Canada (Whitaker & Marcuse, 1994), although there is some disagreement to what extent and in what manner these were manifested. Brookfield (2012), for example, suggests that the "maternal internationalism" (p. 186) exhibited by Canadian

women during this era, while representing all points of the political spectrum—from patriotic, conservative civil defense programmes, to radical protesting against the machinations of war—can still be analysed within a framework which sees the United States / Soviet Union tension as the principle defining feature of this time period. According to her perspective, therefore, familial decisions might be best analysed within the rubric of the enhanced militarism and tension between these two powers, which spilled over into Canadian domestic life. Cavell (2004), however, notes that a Canadian analysis must acknowledge that “Canada’s Cold War was not simply an extension of the one waged in the United States” (p. 5). He suggests that the tensions exhibited during this era “had a particular cultural dimension because it raised issues of national self-representation that went beyond Cold War tensions related to capitalist versus communistic ‘regimes’” (ibid). That is, Cold War debates, beyond ideological deliberations concerning the need to politically and militarily establish particular representations of ‘freedom’ and lifestyle, were, in Canada, “*struggles for control of the symbols of legitimacy in Canadian society*” (Whitaker & Marcuse, 1994, p. 24, emphasis in original). These scholars’ simultaneously overlapping (in terms of the acknowledgement of the hegemonic influence of American Cold War ideology and praxis in Canadian culture), and oppositional (in regards to Cavell’s call to move beyond the capitalist / communist dichotomy within which many Cold War analyses are rooted) perspectives suggest that analysis must include both an acknowledgement of the Cold War as an American-driven phenomenon which had profound influence throughout North America, and of the particularities of its manifestation in Canadian culture and ideology³. Indeed, a more accurate framework might name this era not only as the ‘Cold War’ within Canadian history, but as a time period within which Canadian politicians grappled with the country’s own political and social concerns within the more dominant framework of Cold War

tensions as played out south of the border. Accordingly, my analysis in this chapter includes the premise that both the driving exemplars of Cold War ideology, such as pervasive militarization on a global scale, as well as the more subtle, yet broadly-felt manifestations of the discourse particular to this time period in Canadian history, were influential in Canadian social and political life. Moreover, I suggest that these manifestations were connected, materially and discursively, to processes of institutionalization.

This chapter addresses four principle themes. First, I will address the justification and manifestation of policies of ‘containment’, the overarching approach to the ubiquitous threat of the ‘other’ in both public and private life during this time period. Containment, a term first coined by Kennan in the late 1940s, refers to policies and processes of restraint and surveillance used against particular, ‘othered’ societal groups who were seen as a risk to the hegemony of capitalist state administration (Brookfield, 2012; May, 2008)⁴. Policies of containment, while largely framed in the broad militaristic and patriotic rhetoric of the Cold War and thus seemingly distant from the intimacy of individual lives and families, had a significant influence on normative boundaries concerning work, gender, and sexuality, and thus played a role in familial discernments around ‘problematic others’ during this time period. Second, and stemming from the first theme, I will reflect more purposively on the ubiquitous normativity which intensified during this period, rendering adaptation, as opposed to resistance, as the exemplar of patriotic and acceptable behaviour, and which influenced societal participation in political mechanisms which served the ongoing maintenance of the state. Third, I will do a more intense reflection on the re-emergence of traditional family and “gender regulation” (Kinsman, 2004, p. 116) which occurred through this period, and how gender specificity in particular contributed to the disempowerment of women and their perceived capacities within the family. The revival of

traditional family and gender roles may have influenced families' willingness and self-perception of their capability to care for a child with a disability. And finally, I will examine the emergence of professional expertise during this era, the specific geographic and consumer shifts which contributed to this trend, and how this phenomenon played a direct role in the care of children with intellectual disabilities.

Threat of the other and the discourse of “containment”

Historical representations of the time period immediately following the conclusion of the Second World War frequently suggest a new era, a time of renewed hope for the possibility of a global order within which negotiated and long-lasting peace might at last be realized after decades of global uncertainty (Egerton, 2004; Guest, 1999). As discussed in the previous chapter, people who had survived the horrors of the war and had experienced significant personal loss were determined that notions of citizenship, essential to the establishment of a just and peaceful global body politic, must be expanded to include social and political rights for all people, including people with disabilities and others who had historically been marginalized (Guest, 1999; Simmons, 1982). Growing awareness of the social and political obligation to ensure the rights of all people was countered, however, by the significant and indeed, more powerful global discourse concerning mounting tensions between forces of global capitalism and communism, and the emergent North American obsession to contain the perceived threat of communism. Indeed, while feminist and civil rights movements in the United States and Canada were rooted in suffragette movements which had made important gains in the years prior to World War I, it was not until two decades after the end of the Second World War that activists, frustrated by decades of military stockpiling, rhetorical threats, and wars waged on foreign soil on behalf of the ideological convictions of global superpowers, were able to make headway in

the acquisition of human rights for all members of society (Brookfield, 2012). Thus, while aspirations for justice might have been well-rooted by the conclusion of the Second World War, these were readily opposed by the tense ideological and military stand-off between the United States and the Soviet Union⁵.

Indeed, as Egerton (2004) notes, despite the movement within Canadian political circles to work towards a Canadian Bill of Rights, following the example of the Universal Declaration of Human Rights in 1948, the politics of the Cold War soon saw consecutive post-war Canadian governments placing a “priority on fighting communism rather than advancing human rights” (p. 451). Moreover, Canada’s relationship with the United States during this time period was marked by both ambiguity and acquiescence to military demands (Whitaker, 2004), and “Canadian integration in American military strategies and structures” (ibid, p. 40) made it increasingly difficult for Canada to “take an independent role as diplomatic peacemaker” (ibid). The binding within Canadian politics to the precepts of the Cold War, while played out within an international forum, also left little room, at least within the first two decades following the Second World War, for domestic factions to demonstrate their resistance to ideologies of threat and military preparedness. Notwithstanding some pockets of anti-war resistance which began to demonstrate their position during this time period and continued to do so throughout the more politically-charged 1960s and 1970s, the general sentiment throughout the population reflected the government’s priority to contain the perceived threat of communism (Brookfield, 2012; Roberts, 1989).

Much of the rhetoric of the Cold War revolved around the notion of ‘threat’. Perceived threats included the imminent spread of communism throughout the global world order, which was framed as the potential abolishment of an idealized and consumer-driven way of life, and of

annihilation through nuclear attack. The notion of ‘threat’, embedded within a citizenship framework marked by militarism, patriotism, and adherence to normative codes of behaviour, enabled a discourse of self-protection against an enemy which hovered, often unseen yet imminently ready, to destroy the post-war future. The presumed threatened existence of the North American way of life encouraged the establishment of cultural sites within which people could find security, safety, and protection (May, 2008). Thus, national preoccupations with bringing foreign influences under control and preventing the spread of communism were played out domestically through the establishment of secure and protective enclaves—most notably, the suburban home and the nuclear family. The family, and the home within which it was situated, came to “represent a source of meaning and security in a world run amok” (ibid, p. 26). The home provided the boundaries within which young families could safely live, for it ‘contained’ (ibid, p. 16) them from the imminent threats poised on the threshold of the North American way of life. Moreover, and inversely, the home and the family stability it represented were seen as tools through which the extent of Soviet influence could be contained and repelled through closely-regimented boundaries. Supported by policy that strengthened the post-war family, the traditional roles embedded within it, as well as its specific cultural and geographic locations, the family came to be seen as “the best bulwark against the dangers of the cold war” (ibid, p. 9).

The perceived threats to domestic and political stability were not limited to external influences, however (Cavell, 2004; Kinsman, 2004; Whitaker & Marcuse, 1994). Indeed, the menace feared by political leaders and the populace alike went beyond concerns regarding the danger of domination and annihilation from adversarial foreign powers, and included those perceived to emanate from within. Retrospectively, analysis suggests that internal threats—“racial strife, emancipated women, class conflict, and familial disruption” (May, 2008, p. 9),

among others, were as much cause for alarm for decision-makers as the threat of Soviet “territorial expansion” (ibid). Rather than regarded as necessary precursors to the establishment of fundamental human rights, nascent ideological movements, many of which originated in groups traditionally marginalized from mainstream society, were interpreted, rather, as threats to the moral discipline of the modern family (Iacovetta, 2006). Accordingly, they were met with a disciplinary response which encouraged the upholding of traditional familial and gender norms via domestic containment, wherein the “dangerous social forces of the new age might be tamed” (May, 2008, p. 16).

Canadian scholars propose that government obsession with these ideological and cultural shifts, seen as threats to domestic and international stability, was the principle conduit through which the effects of the Cold War were manifested in Canada. Cavell (2004) suggests that this time period in our history, beyond the basic polemics of capitalism versus communism, should be characterized rather as a “much broader process of ‘othering’” (p. 4) which both preceded the establishment of the Iron Curtain, and survived beyond the collapse of the Berlin Wall (ibid). This suggests that particular discriminatory practices, which became notably more pronounced during the Cold War, a time period marked by frenetic fears of the enemy within, were already well-established in Canadian social and political circles. Viewing the Cold War era in this way allows for analysis which goes beyond the “dimensions most often examined” (ibid), and allows us to see that practices of ‘othering’ were, indeed, already “deeply rooted in the historical substrata of the nation” (ibid). From this perspective, the Cold War provided a convenient framework for the naming and surveillance of those seen as different, for it justified discriminatory practices in the name of national security, practices which were already engrained within the Canadian political tradition (Kinsman, 2004).

While many individuals and groups were seen as suspect to the government's articulated mission of foreign and domestic security, especially those who opposed military intervention in countries 'threatened' by communism (Brookfield, 2012), the harassment levelled at gays and lesbians was particularly oppressive. Drawing attention to a little-publicized era in Canadian history, Kinsman (2004) notes that the interrogation and sometimes arrest of more than nine thousand gay men by the RCMP in the 1960s (p. 109) is indicative of a broad culture of national surveillance and discipline aimed at those seen as a threat to Canada's national security. According to Kinsman, discrimination levelled at gay men and women during the 1950s and 1960s was justified in order to wean out of government service those who possessed a "moral or 'character' weakness... these 'weaknesses' were defined as an inability to perform oneself as 'normal'. Because queers were defined as being outside 'normality', they were seen as having something to hide, and [were] therefore subject to blackmail" (Kinsman, 2004, p. 117). Although tenuous, this logic was routinely used to rid government service of men and women who, due to their sexual orientation, were seen as threatening to domestic and international stability. Moreover, the suppression of the gay community was regarded by many as an 'acceptable' disciplinary practice, due to its moral undertones, and it opened the way to a more generalized culture of inhibition against any element which might disturb the overall goal to maintain the status quo of the nation state. Indeed, in a brilliant and pointed analysis, Corber (1997) notes (albeit in an American context, but still relevant here), that the "homosexualization of left-wing political activity provided cold war liberals with a mechanism for containing the [growing] demands of women, African Americans, and other historically disenfranchised groups for greater access to the American dream in exchange for their contributions to the war effort" (p. 3 / 4).

Thus, the justified suppression of ‘queerness’ served as a tool to broader mechanisms of discrimination against other marginalized groups.

The framing of gay people is relevant to our purposes here because of its connection to the notion of deviance and the resulting policies of discrimination which were directed at other groups on the periphery of society. As Gentile (2000) notes, “the notion of ‘deviance’ then, was a way to identify not only gays and lesbians, but also women [and, I might add, all other marginalized factions] who resisted or challenged the gender norms and social order prescribed by political and medical experts” (p. 132). Thus, while gays and lesbians were the face of justified discrimination in light of the needs of the state, a generalized culture of ‘othering’, including the marking of deviance and the suppression of difference, became acceptable in the broad cultural and political milieu. Accordingly, while the Canadian government struggled with questions concerning its ambiguous relationship to the United States during this era (Whitaker, 2004), as well as its self-perceived need to establish markers of “national self-representation” (Cavell, 2004, p. 7), the disciplinary work being done ‘on the ground’, invisible to most, did much to suppress what calls there were to implement broader mechanisms of social justice. To refer back to Egerton’s observations from the beginning of this section, within the discourse of national security, there was little room for the advancement of human rights.

To conclude this section, I refer back to the notion of ‘containment’, the regulatory practice of binding presumed disruptive elements within the bigger context of national protection. While May (2008) depicts containment in America as “an overarching principle... that was the key to security” (p. 16), Kinsman (1996) suggests that it might be more accurate within the Canadian historical context to view the “culture of containment as... a culture of regulation” (as cited in Cavell, 2004, p. 13) which normalized the suppression of challenging

factions in order to preserve the “social organization” (Kinsman, 2004, p. 124) deemed necessary for potential confrontations with enemies both external and internal. The regulation to which Kinsman refers worked in symbiosis with the normative culture pervasive during this era, two factors which contributed to familial discernment regarding the care and treatment of family members with disabilities.

Norms: Adaptation versus resistance

The culture of normativity which marked this era meant that people or social factions which fell outside acceptable norms of opinion, appearance, and behaviour were considered suspect in the quest for national security. While harassment directed against the gay community is a preeminent example of the repression which marked this time period, there were other cultural locations within which discrimination against seemingly disparate elements was located. Within this restrictive milieu, any deviance became suspect in the larger nationalist project of protectionism and preparedness. With the broad ideological reasoning typical of this era, those who challenged the status quo were considered unpatriotic and potential communist sympathizers (Brookfield, 2012). In the immediate post-war years, a culture of “reification” (Kinsman, 2004, p. 113) of the enemy and the plans concerning its containment meant that those who questioned the reasoning behind political decisions were consistently painted as disruptive elements and as dangers to the security of the nation. Thus, in another ironic twist to the logic with which this era is imbued, “peace” became a “contentious term... as it was considered by many Canadians to be a concept more in line with communism than democracy” (Brookfield, 2012, p. 76). That is, to speak “openly about peace was subversive” (ibid). Adherence to the status quo denoted patriotism, while challenge, even if it called for a reduction in violence-preparedness, research into the effects of nuclear fall-out (Brookfield, 2012), or the allocation of

funds towards social inclusion as opposed to military might, marked one as seditious (Whitaker & Marcuse, 1994).

Accordingly, the overwhelming acceptable civic response during this era was acquiescence, not resistance (Roberts, 1989; Runté & Mills, 2006). As May (2008) notes, the general tenor of post-war life was distinctly “apolitical” (p. 17). Social critique was not encouraged, particularly from marginalized groups such as women, who had much to gain from social change, yet instead played significant roles in the maintenance of the Cold War ethic. Particularly in the decades immediately following the end of the Second World War, compliance with the Cold War consensus (May, 2008, p. 166) was the normative standard, and challenge was interpreted as a threat to the whole patriotic venture.

Contextualising the postwar family within the larger political agenda of conventionality helps elucidate the consternation that families would have faced in the event of the birth of a child with a disability. The culture of conformity was expansive and worked to consolidate the hegemony of the white, middle-class Canadian family (Gleason, 1999a, 1999b). The “universalized standards of childhood” (Helleiner, 2001, p. 150) which marked this period included standards of race, gender and ability, and “contained costs for those who did not meet with its standards” (ibid). As Helleiner notes, those located outside of the explicitly gendered (male), racialized (white) and ableist norm were, during this time period, “in a much more ambiguous relationship with nation-building” (ibid), and were regarded as non-essential players in the establishment of a strong postwar body politic (Iacovetta, 2004). In Gleason’s (1999b) words: “the body acted as a stigmatizing text; inferiority was written on their bodies... the body was an inescapable marker from acceptable... society” (p. 122). The right course of action, therefore, as upstanding citizens, was to produce “the right kind of children” (Helleiner, p. 149).

Within this agenda of conformity, resisting the acceptable and professionally-backed route of institutionalization and agitating for increased community-based services for children with disabilities was a difficult endeavour indeed. In an era during which norms were deified, deviance was suspect, and people's compliance was a demonstration of national allegiance, challenging expert advice to "put the child away" could be interpreted as a discomfiting display of unpatriotic defiance.

Postwar families, marital survival, and decision-making in the Cold War home

Cold War ideology fostered the "symbiotic connection between the culture of the cold war and the domestic revival" (May, 2008, p. 13). Domestic containment, while regarded as an essential tool in the control of the spread of communism, also served as a cultural location for the re-emergence of a "conservative family ideology" (Iacovetta, 2004, p. 78). Indeed, the nuclear family, and the gender hierarchies and distinctions embedded within, were "part of the highly charged turf on which moral victories against communism were fought" (Iacovetta, 2006, p. 174). Despite significant gains by the first wave of feminists in the early part of the twentieth century, including prewar trends of later marriage, fewer children, and women working outside the home to support families hit by the depression, the immediate postwar years were marked by a distinct reversal: marrying at a young age, having several children, and embracing distinct divisions of labour based on traditional gender lines (Brookfield, 2012; May 2008). Indeed, despite the possibility for a "radical restructuring of the family" (May, 2008, p. 24) which had emerged during the depression and the war, the postwar populace embraced domesticity and traditional gender roles as a means of strengthening the nuclear family, which in turn was seen as a means to build national security. With the tenuous logic typical of this era, traditional domesticity and strict gender divisions were regarded as significant connectors between strong

families and a strong nation (Gleason, 1999a, 1999b, 1997; Helleiner, 2001; Iacovetta, 2006; Thorn, 2009). “Prosperous, content, and united families were... the result of and the contributors to a strong, flourishing nation” (Brookfield, 2012, p. 53 / 4). Thus, North American families turned to conventional and distinctive roles: men worked outside of the home at hierarchically-organized jobs, and women stayed home as full-time homemakers, caring for children and organizing the running of the household (Iacovetta, 2004; McPhail, 2009; Runté & Mills, 2006).

The return to traditional domestic arrangements has also been analysed as part of a broader societal effort to ensure returning veterans’ re-integration into regular civilian life with prescribed and restorative roles (Runté & Mills, 2006). Efforts were made to ensure men’s resumption of positions as responsible and contributing citizens (May, 2008, p. 86) and to restore their sense of masculinity and purpose, hence minimizing the possibility of “crime, perversion, and homosexuality” (May, 2008, p. 86). Bluntly put, women were encouraged to return to the home front in order to make room for their men; “the domestic messages that prevailed... now focussed on the needs of the returning veterans” (ibid, p. 65), and women were encouraged to assume the role of the resilient home-builder and emotional sounding board for their returning husbands. Further, the establishment of domestic enclaves with prescribed gender roles wherein women remained subordinate ensured men’s authority within a specific cultural location.

Within this milieu, the family was central. The family home, within which men gained needed respite from their contributions to the larger project of national preparedness, and within which women played supportive roles, became a nexus of security and preparedness within the potential chaos of nuclear war, and was an antidote to the perceived threat of familial breakdown due to rapid urbanization and modernization (Gleason, 1997). As discussed in an earlier section, the home served as a site of ‘containment’ in two distinct ways: as an enclave in the event of

war, and as a solution to the social disarray that the postwar lifestyle was feared to be introducing into North American families. Accordingly, to use Brookfield's (2012) terminology, the "home front became the front line" (pp. 51-69). With the chaotic uncertainty of no known location wherein this 'war' would be waged (Whitaker, 2004), successive Canadian governments encouraged a generalized preparedness in which family homes would serve as secure enclaves, the families within equipped and ready to withstand enemies, from both within and without (Runté & Mills, 2006). Thus, a stable family home and a house "filled with children" (May, 2008, p. 26) had as much to do with establishing a strong security state as it did with fuelling the romantic postwar notion of returning war veterans and their sweethearts creating a home together.

Moreover, as briefly discussed above, this ideology extended into the kind of children who should be produced and their perceived potential to contribute to cold war efforts. "Strong and able offspring" (May, 2008, p. 96) were seen as "an essential ingredient to winning the Cold War" (ibid). Families were expected have several healthy children, for "maintaining strong, healthy bodies was also seen [as] part of families' civil defence plan" (Brookfield, p. 58). Accordingly, public health endeavours launched during this era, while seemingly promoting reasonable and desirable lifestyles of healthy eating and physical exercise, also served, via discursive connections between health, capability, and "capitalist production and militarism" (McPhail, 2009, p. 1026), to promote the political and economic mandates of the Cold War (ibid). Further, the emphasis on capitalist, office-based contributions, particularly through male-dominated bureaucratic and managerial positions (May, 2008), in combination with rapid changes in the agrarian focus of many rural communities, resulted in a significant shift towards urbanization and suburbanization during this time period (Thorn, 2009). The decrease in farm-

based economies and family-run businesses within small communities meant that the meaningful roles that children with disabilities might have been carrying within the family environment prior to the war were no longer as available. This narrowing of options for people with disabilities in their home communities, in combination with the discursive emphasis on effective contribution, made it much more difficult for families to imagine keeping their child at home and having him or her maintain an effective role in the community⁶. In sum, therefore, physical and intellectual capacities in general were considered within a rubric of evaluation which assessed the potential of various social members to contribute to the larger ‘war effort’.

This restrictive milieu might explain, in part, the glacial pace at which the provincial government moved to address the concerns of parents with children with disabilities in the immediate postwar decades, as discussed in chapter four. Moreover, reflection on this era reveals a dark irony. Despite public awareness of the devastating effects of eugenic policies, including extermination, applied within Nazi Germany on several groups of marginalized people, including people with disabilities, throughout the Second World War (McLaren, 1990), eerily similar calls for race purification continued to be voiced within certain jurisdictions of North America during this period in feeble arguments linking a weak populace to being overrun by the communist threat (Brookfield, 2012; May, 2008). The nationalist vision to build a strong and secure nation state was narrowly defined, and was not inclusive in its mandate.

There are two further features of the postwar consolidation of traditional domestic arrangements that are relevant to our purposes here. First, women’s containment within the home can be seen as a significant factor in their ongoing subordination, which can be linked to assumptions regarding women’s competence and the extent of their capabilities. Feminist scholars have pointed out that women’s absorption of the majority of domestic and childcare

responsibilities, as well as discourse which vehemently opposed work outside of the home because of the feared consequences of dysfunctional families and delinquent children (Gleason, 1997; Iacovetta, 2004; Thorn, 2009) played a significant role in women's absence in the public arena, and a devaluation of both their public and familial contributions (Runté & Mills, 2006). Prevailing discourse denied women the full extent of their authority in both public and private spheres (McPhail, 2009), and continued to reinforce the notion of women's incapacity in particular areas, particularly those that were physically and emotionally taxing. These assumptions, in combination with the lack of community supports for children with disabilities and their families in the postwar period, underpinned prevailing perceptions that many women were not up to the challenge of raising a child with a disability, unassisted, in the home. As the findings from this study will indicate, the simplified response to the challenge of caring for a child with a disability was, in many cases, to name it as a task too large, both physically and emotionally, for the limited abilities of women. As was typical of the apolitical nature of social discourse during this era, the response to the difficulties that women encountered was not to challenge the status quo and push for change that might have alleviated the pressures women faced, nor to provide better opportunities for children with disabilities in the community, but to assume instead that families were better off placing the child outside the home into institutional care.

Second, the specific gendered domestic arrangements during this era played a significant role in how decisions were made within the family home, and to what end (McPhail, 2009; Runté & Mills, 2006). Notwithstanding the fact that women's realm was the home, men remained principle decisions-makers within the family (Gleason, 1997, 1999a, 1999b; May, 2008; Thorn, 2009). While women would have made most of the day-to-day decisions regarding

their children's care, there were limits to the extent of their authority. The literature to date has not sufficiently investigated decision-making in families regarding the specificities of institutionalization, nor the extent of the interaction between family needs and dynamics, and the prevalent discourses regarding the care of children with intellectual disabilities. What is known, however, is that the predominance of prevailing discourses around the location of authority within the home, and the ideological and practical need to ensure the survival of the institution of marriage, would have been significant factors here.

Cold War ideology was heavily dependent on the survival of traditional cultural institutions, and great efforts were made to ensure the continued existence of marriage and family (Iacovetta, 2006). As cornerstones in the edifice of North American stability, married couples, and women in particular, worked hard to maintain their marriages, for they "had invested a great deal of their personal identities in their domestic roles and were not willing to abandon them" (May, 2008, p. 38). Many women, in light of the significant personal sacrifices with which they had imbued their marriages (ibid, p. 189) were likely to acquiesce within the relationship in order to ensure its survival, particularly when stressful situations threatened to undermine it (Brookfield, 2012; Iacovetta, 2006; May, 2008). Seen in this light, the decision to remove a child from the family home, if the care of that child was adding tension to an already-fragile relationship, the survival of which was paramount in the broader context of cultural and national integrity, is more understandable (Sherman & Coccoza, 1984).

Moreover, within the context of concern to raise the "right kind of children" (Helleiner, 2001, p. 149), the desire to ensure that the futures of non-disabled siblings were not impinged upon or threatened by the presumed burdens of a disabled brother or sister would have been paramount (Lobato, 1983; Sherman & Coccoza, 1984). As Gleason's (1999) extensive research

on families during this era indicates, the narrow and expert-informed parameters for the model family “pathologized those outside the ideal” (p. 81) and provoked consternation when families were not able to live up to idealized expectations. While there is little literature from the postwar period that discusses disability beyond its most clinical and medicalized aspects, the literature which attempts to address broader issues does so primarily from the perspective that the introduction of disability to the family is a disruption which must be addressed in order that the pre-existing integrity of the family be re-established (Farber, 1959, 1960; Holt, 1958; Jordan, 1961). That is, postwar writing on families within which one member has a disability concerns itself almost exclusively with the (principally negative) effect of a disabled child on his or her family and siblings, indicating a presumed research bias which locates the ‘problem’, in its entirety, in the child with the disability:

... the presence of a retarded [*sic*] child has a serious impact on the family. Marital integration suffers when a retarded child lives with the family... the retardate’s impact on the siblings [are] as follows: the younger retardate affects the siblings’ adjustment most... (Jordan, 1961, p. 48)

Indeed, Lobato (1983) notes that within the body of literature in the three decades immediately following the Second World War, there exists a consistent assumption that the siblings and families of children with disabilities experienced “more stress than most” (p. 348), and were at “greater risk for psychological problems” (ibid). In accordance with the overarching ideological discourse of the time, the goal of research which investigated children with intellectual disabilities and their families during this era was to describe current situations, and to determine the impact of disability on those considered ‘normal’, never the reverse. Moreover, postwar

researchers tended to remain silent on the critical and structural reasons for familial strife, and generally did not point to potential societal changes that might have improved situations for those affected by disability in some way⁷.

Thus, during this era, families, and women in particular, were compelled to adapt to a discourse which promoted the survival of the marriage and the idealized family. Families learned not to resist, but rather to adapt to the social and political institutions which facilitated that survival, in spite of its potential costs in other areas. In some situations, therefore, couples may have been more likely to decide to remove a child with a disability than to grapple with alternative arrangements that might have allowed the child to stay at home, albeit with the difficulties that such needs might have presented to the marriage and the family.

The premise of adaptation is linked to another postwar phenomenon which had significant bearing on familial decisions regarding the care of family members with disabilities. Amid fears of the breakdown of the family (Gleason, 1999a, 1999b; Thorn, 2009) and the imminent threat of cultural implosion at the hands of external and internal forces (Brookfield, 2012), ‘experts’, particularly in auxiliary professions such as social work, rehabilitation, and special education, began to secure their positions in the public arena as essential figures in the task of coping with emergent realities. In accordance with the prevailing view that in difficult circumstances it was more important to adapt than to address their social and political origins, experts and the therapeutic models which they embraced encouraged the postwar populace to accept the status quo, and to mould their own family situation within its boundaries. For the first time, the ‘expert’ phenomenon firmly secured itself in the public realm, and professional expertise began to have significant influence on the culture and workings of the family.

The nuclear family and the role of the ‘expert’

In regards to the emergence of the postwar professional in areas such as health, education, counselling, and psychology, there are two issues which arise. First lay the concern that traditional family constellations would not survive amid postwar possibilities of nuclear annihilation and rapid and unrestrained social change. Prevailing anxieties suggest that the postwar populace lived in an era which facilitated family and social breakdown (Brookfield, 2012; Gleason, 1997; Thorn, 2009), creating a space for the emergent expert, willing to impart professional skills on families disposed to maintaining the postwar family consensus. As already discussed, discursive constructions embedded beneath the notion of the necessity of the expert included the perception that ‘well’ marriages meant ‘well’ children (and vice-versa), and that the strength of the institution of the family leant credence to the strength of the nation (Gleason, 1999a, 1997; Thorn, 2009; Brookfield, 2012; May, 2008). Important to our purposes here is the notion that ‘wellness’ was synonymous with normalcy, and that the political and cultural investment in therapeutic interventions had a great deal to do with reinforcing hegemonic ideals of the white, middle-class, successful and able Canadian family (Gleason, 1999a, 1997; Helleiner, 2001). Accordingly, in the postwar years there was a flurry of development in auxiliary, ‘helping’ professions, ostensibly to assist in the recommended course of action for children with disabilities and others with similarly unfortunate diagnoses. Retrospective reflection on these professions within the context of postwar ideology, however, suggests they concomitantly served the broader notion of establishing “sets of normative standards and expectations” (Gleason, 1997, para 32), part of the overall postwar discourse of a strong, fortified and healthy nation.

In addition, scholars note that to suggest that the discourse of professionalism emerged solely from the hegemonic requirements of the age is to ignore the reality that the ‘expert’ opinion to which I refer was part of the “social practice that actually [brought] itself into being” (Kinsman, 2004, p. 109). That is, the professionalization of the task of raising a family which fulfilled the normative expectations of postwar Canada, and the expert advice deemed essential to its successful completion, were in a symbiotic and mutually-sustaining relationship. In other words, professionals played a role in creating the normative discourse which validated their own existence (Gleason, 1997; Thorn, 2009). Within this context, and with the ever-expanding circle of children deemed in need of some sort of educative, psychological, and domestic assistance, long-term institutionalization remained a viable option, an option that was generally not opposed by the growing professional establishment. As families gradually relinquished their internal expertise to that of experts (Gleason, 1997, 1999a, 1999b), particularly as medical and technological advances enhanced the survival of children born with increasingly complicated conditions, institutions designed for long-term placement remained as fixtures on the landscape of possibilities for postwar family survival.

Second, a relatively under-discussed yet significant geographic phenomenon emerged in the postwar era which, although not normally considered in discussions concerning the institutionalization of people with intellectual disabilities, played a role in its continued practice. The development of sprawling, suburban-based housing developments which utilized huge tracts of land and were dependent on extensive networks of roads and car ownership played a specific role in the practical aspect of Cold War life (Whitaker & Marcuse, 1994). Beyond the lure of abundance and space that such arrangements offered, May (2008) suggests that political leaders also saw suburban neighbourhoods as another means to minimize the potentially devastating

impact of a nuclear attack. Suburban planning relied upon the decentralization and depopulation of urban cores, thus preventing the “concentration of residences or industries [which might act as] potential targets” (p. 161). Vast highway networks were needed to connect expansive and distant neighbourhoods, which would allow for efficient ‘evacuation’ of large tracts of land in case of foreign attack.

The decentralized and expansive nature of suburban developments meant that for the first time in the modern era, extended families and the traditional lines of communication and support typically rooted therein were suddenly distanced from each other (Thorn, 2009). No longer was the expertise of parents and grandparents as available to young men and women who were beginning families of their own (Iacovetta, 2006; May, 2008). Women in particular were affected by this phenomenon, as they were largely isolated from peers and family from whom they might have gained significant practical and emotional support. Loss of the knowledge that would have been available to previous generations via more intense domestic arrangements, in combination with the figurative and practical distance between families needing to access it, particularly in regards to women, meant that many families were not party to informal yet vital networks of support that might have sustained them through the understandably challenging task of raising a child with a disability. The increased demarcation between individual homes and families, and the distinct loss of ‘fluidity’ that former, more densely populated and generationally-rich settings would have offered resulted in a marked diminishment in the informal sustenance that women and families would have previously been able to rely upon.

Further, through their relegation to the maintenance of the suburban home, women were removed from forums of public discourse and were thus limited to “individual and psychological terms” (Runté & Mills, 2006, p. 703) in the articulation of personal or public grievances, as

opposed to having access to public arenas of social and political critique. Accordingly, gaps in shared knowledge and practical support, exacerbated by isolating socio-cultural and geographic developments, left significant space in women's and families' lives for the opinions of 'experts', as discussed above (Iacovetta, 2006; Simmons, 1982; Thorn, 2009). Indeed, "the reliance on expertise was one of the most striking developments of the postwar years" (May, 2008, p. 30), and the link between adherence to professional opinion and one's moral and patriotic standing was explicitly suggested via discourses of both responsible citizenship and the respect and authority that experts commanded in the public arena (Iacovetta, 2006, Thobani, 2007; Thorn, 2009). Moreover, as Trent (1994) and Simmons (1982) have suggested, the proximity with which professionals in the community worked with institutional supervisors and administrators, government officials responsible for their funding and oversight, and members of provincial parliament, would have played a role in continued support for referrals to institutional care.

The trends discussed above suggest that families faced with decision-making regarding the care of their children with disabilities had many influences with which to contend. Ongoing admission to institutions during the postwar era was not only due to the lack of community support and acceptance of people with intellectual disabilities, as discussed in chapter four, nor to the hegemonic idealization of the strong, beautiful, and content family. Institutional admissions were underscored in a very practical way by government policy which consolidated particular elements of postwar life, including the development of suburban living and the resultant isolation of families and women, and the co-emergent authority of professional opinion and expertise. In the words of Runté & Mills (2006), "everything had to be learned" (p. 703); the "learning" expected by authorities was individualized, professionally-directed, and dependent on the assumed co-operation of 'good', upstanding families.

Conclusion: Family fronts, the politics of shame, and when there was no ‘choice’

As the above discussions have indicated, the idealized postwar family was constituted by traditional gender divisions, male authority, female homemaking, and strong, healthy children (Gleason, 1999). Its discursive production was both supported by and offered validity to the grander narrative of the need for patriotic families in order to stem the threat of communism, internal strife, and the degeneracies of modern society. Within this restrictive narrative, there was little room for families which fell outside idealized designations. Particularly within the Canadian narrative of progress, within which intellect was a predominant marker of one's potential for contribution to the modernisation of the country, intellectual disability would have been seen as a hindrance and was framed within a deficit perspective. A presumed lack of intellect and the designation of life-long dependency was a perversion of the narrative of progress that the country felt compelled to abide by during this era, and a child with a disability was a signifier of what a family was unable to contribute to the essential thrust of development. Accordingly, during this era, there were most certainly mechanisms of shame with which families with disabled family members had to grapple. While the empirical research to date in this area is scant, and the findings section of this dissertation will address the element of shame as experienced by actual families during this time period, the context of the Cold War decades as discussed in this chapter suggests that the dynamics of public humiliation might have had some bearing on the decisions that families made regarding their children with intellectual disabilities.

And last, this chapter would not be complete without some mention of situations in which the decision to place a child in an institution was not a decision at all. The preceding discussion has dealt primarily with the social, cultural, and political conditions surrounding postwar families and how these conditions might have contributed to decision-making

concerning persons with intellectual disabilities. For families that fell within the hegemonic ideal of the white, heterosexual middle class, the decision to place a family member in an institution would have been influenced heavily by the strict normative codes that governed much of Canadian social and political life during this time period. While any decision to remove a child from the family home must have been extraordinarily difficult, for those who occupied a privileged position within Canada's white middle class, this decision was likely affected most deeply by the ignominy of having a child with a disability, and the related discomfiting encounters with other families who were better able to present themselves within the public normative ideal. While difficult, families in situations such as these would have been able to maintain at least some semblance of choice.

For many families, however, the decision to place a child in an institution was not theirs to make. As Canadian scholars Strong-Boag (2011, 2007), Gleason (1999a, 199b, 1997), Helps (2007), Iacovetta (2006), and Helleiner (2001) have indicated, discourse surrounding Canadian nation-building throughout the twentieth century was pointedly skewed in favour of the hegemonic norms this chapter has discussed, and the threshold for selection processes for institutionalization under the auspices of public health and government agencies was significantly lower for people of First Nations origins or of low socio-economic status. The conflation between poverty, ethnicity, and intellect, and one's assumed ability to contribute meaningfully to Canada's larger patriotic project was a significant factor in decisions to place children in institutions, decisions which lay outside of many families' control. As the findings section of this study will indicate, underlying forces behind institutionalization varied significantly between different groups of people, and institutionalization processes were heavily influenced by socio-economic status and ethnicity. While it is beyond the scope of this study to

analyse all aspects of the institutionalization tragedy in Canadian history, it is important to bear in mind the significant overlaps between various groups of people who suffered under the moral regulation and normative standards typical of the latter half of the twentieth century in Canada's history.

This chapter concludes the social, political and historical contextualization of institutional processes in Canada which were relevant to the families at the centre of this study. The next chapter will present the methodology engaged for this project, after which the findings of the study will be presented and analysed.

Introduction to Part II

Part II presents the primary findings from the research, and provides theoretical analysis of the major themes which emerge. This project included five distinct groups of participants: survivors of institutionalization, siblings of survivors, parents of survivors, former staff at institutions, and key informants¹. Initially, each group will be dealt with separately; that is, the principal themes which emerge from within each group will be discussed and analysed in separate chapters. Broader analysis involving all five groups and the themes which emerge from a more comprehensive perspective will be drawn following each group analysis, in Chapter Twelve. This process was chosen because the specific characteristics and distinctive features of each group contribute to variances in experience and understanding. Upon examination, it became evident that broader conclusions could not be drawn without first examining the more immediate and intimate details of the experiences of each group of participants. By comparing the findings from within each group and examining them with a view to their simultaneous yet distinct phenomenology, it was hoped that patterns and commonalities might emerge, gaps might be identified, and some of the implications of institutionalization processes during a particular time period might be better understood.

Participant findings will be addressed in the order listed above: survivors, siblings, parents, former staff, and key informants. In this way, I move from sites of immediate and intimate experiences of institutionalization to those gradually more removed. I acknowledge that within this constellation, siblings and parents could be reversed in regards to their relative proximity to the survivors. Indeed, parents might be considered ‘closer’ to the children who were institutionalized than their siblings, and were undoubtedly closer to the decision to institutionalize. However, it seemed appropriate to place the reflections of siblings directly

beside those of their brothers and sisters, all of whom were children as this phenomenon evolved within their families, and who expressed the impact of the removal of their first play-mates most acutely. Thus, the discussion moves through family constellations—survivors, siblings, parents—to those who worked with institutionalized individuals and their families, and finally addresses the insights of those who were observers, activists, or educators during this time period.

Chapter Six: Methodology

Introduction

The methodology for this project will be discussed under three principal headings, each of which represents a distinct phase of the research process (Denzin & Lincoln, 2013). First, the study's principal research paradigm and its "underlying philosophical assumptions" (Mertens, 1997, p. 5) will be discussed. This section begins with a brief summary of qualitative research in general, the overall 'umbrella' strategy of inquiry (Creswell, 2009, p. 5) used, and includes a brief explanation of the particular theoretical 'lens', or orienting perspective (ibid, p. 62) with which I engaged throughout the research process. Second, I describe the specific methods used for data collection, including ethical considerations, recruitment strategies, sample characteristics, and interview procedures. Last, I identify strategies used for data analysis, including how themes were drawn from within and among different groups of participants. The chapter concludes with other methodological details, such as the time frame and setting for the research. Themes and theoretical concepts identified from the research (Charmaz, 2013) will be presented in Chapters Seven to Twelve.

Qualitative Research Design

In general, qualitative research is the process through which "the researcher seeks to establish the meaning of a phenomenon from the views of participants" (Creswell, 2009, p. 16). Qualitative research attempts to interpret data "in order to elicit meaning, gain understanding, and develop empirical knowledge" (Corbin & Strauss, 2008, p. 1). The use of qualitative methods is appropriate for this research due to its stated intention to explore the phenomenon of institutionalization and its effects on family relationships and understandings of disability, an area which calls for open-ended questioning, exploratory techniques, and the investigation of

participant meanings, all essential elements of a qualitative approach (Creswell, 2009).

Moreover, qualitative methods encourage researchers to document both the phenomena of interest, in this case, institutionalization and its impact on those who have experienced it directly or indirectly, as well as the “agentic processes—the *hows*—by which social reality [relevant to this research] was constructed, managed, and sustained” (Holstein & Gubrium, 2013, p. 255). This is particularly relevant here, as this study is an interrogation of the interactions between the development of institutional care and its attendant political, social, and cultural conditions, and the manifestation of these factors in peoples’ direct experiences.

Historically, disability researchers from the social model perspective have advocated for the use of qualitative methods in any research which involves people with disabilities (Barnes & Mercer, 1997; Bury, 1996; Oliver & Barnes, 1997). Its emphasis on determining the meanings that research participants bring to their lives and the particular situations in which they find themselves, as well as its use of inductive analysis—that is, analysis in which themes and concepts emerge from the collected data, as opposed to the establishment of a priori theoretical assumptions (Creswell, 2009)—allows qualitative research to be a tool in the challenge to alter the mode and means of knowledge production (Barnes & Mercer, 1997), and to shift the historically oppressive relationship between the objective, non-disabled ‘researcher’ and the disabled research ‘subject’ (Bury, 1996).

Moreover, disability studies has grappled with Oliver’s call for an emancipatory research model (Oliver, 1992)¹, which insists that research not only be driven and directed by people with disabilities, but that it contribute to overall, liberatory goals of “independent living, social inclusion, and anti-discrimination” (Beresford & Wallcraft, 1997, p. 67). Researchers in the field have debated both the merits and drawbacks of a specific emancipatory model ² (Bailey, 2004;

Barnes, 2003, 1992; Barnes & Mercer, 2004, 1997; Davis, 2000; Mercer, 2004; Oliver, 1992; Oliver & Barnes, 1997; Scott-Hill, 2004). While this project provides historical and personal perspectives on a significant historical practice directed against people with disabilities, and may at some point in the future contribute to relevant policy changes to improve the lives of people with disabilities, it cannot be considered emancipatory, but rather as a forum within which peoples' experiences of institutionalization were safely articulated. My intention, in summary, was to conduct research that is "accountable to disabled people" (Barnes, 2003, p. 122), that it be committed to the goal of non-oppression of people with disabilities, and that it be conducted with principles of "openness, participation, and accountability" (Barnes, 1992, p.12).

Research paradigm

This research assumes a social constructivist worldview as its principal methodological framework. A constructivist paradigm assumes that "knowledge is socially constructed by people active in the research process" (Mertens, 1997, p. 11), and that the role of the researcher is to understand "the complex world of lived experience from the point of view of those who live it" (Schwandt, 1994, p. 118, as cited in Mertens, p. 12). A social constructivist paradigm is appropriate here, as this study is an attempt to discern the meaning that a particular group of people (those who experienced institutionalization processes, either directly or within their family) attribute to a particular phenomenon (the institutionalization of people with intellectual disabilities). Moreover, this perspective acknowledges the constructed nature of the phenomena with which we are interested—namely, institutionalization and intellectual disability. A social constructivist approach acknowledges that understandings of institutionalization and disability are products of historical, socially-mediated interpretations, and that they vary profoundly from era to era and from group to group. As was addressed in particular in the introduction to this

dissertation, I bring my assumption of the constructed nature of disability to this research, and work under the supposition that this has had a significant impact on the various models of care which have evolved historically.

Further, a social constructivist approach disputes the claim for a-priori findings or conclusions. It does not assume the existence of pre-existing meanings or results within a phenomenon. Rather, it acknowledges the ongoing uncovering of significance while a phenomenon is explored and interrogated (Creswell, 2009; Denzin & Lincoln, 2013), and recognizes that different meanings will emerge as findings from different groups are scrutinized. This, therefore, leaves open the possibility for the creation of new knowledge and for “dissensus” (Mabry, 2002, p. 148) within the research findings, a situation highly possible when one considers the vastly different interpretations that various participants could bring to the phenomenon in question.

Last, a social constructionist approach allows a redress of the historical imbalance of interpretations that have dogged the history of institutionalization. That is, until very recently, historical accounts of institutionalization processes in Ontario were not given by those who experienced it directly or within their family constellations, but rather by those who dictated its parameters—in particular, the provincial government, which owned and operated the facilities, and the medical establishment, which participated to a large degree in their continuation via ongoing recommendations for their use (Simmons, 1982). A constructivist paradigm, therefore, allows those most profoundly affected by institutionalization to have a forum within which to convey their experiences, thus encouraging a more thorough and inclusive analysis.

Theoretical lens: Advocacy

As Creswell (2009) has indicated, the particular theoretical perspective which a researcher assumes provides an orienting ‘lens’ to the project, informs the “shapes and types of questions asked and how data are collected and analysed” (p. 62), and provides the position from which a researcher might make a “call for social action or change” (ibid). While my intention was to explore the phenomenon of institutionalization as broadly and thoroughly as research parameters allowed, thus necessitating the inclusion of various groups of people, including some who might be construed as being in favour of institutionalization, I undertook these tasks with the assumption of an advocacy lens. That is, while open to varying interpretations and experiences, I worked under the presumption that the narratives of those most affected by institutionalization yet historically excluded from its interpretation, that is, those who were themselves institutionalized, must be brought into the public arena. With the trust endowed me by the participants who agreed to share their stories, this project has therefore served as a vehicle through which I can speak on behalf of people who have heretofore been omitted from the historical record. Further, the historical nature of this study suggests that it must be approached as a window through which we can better understand institutionalization processes, yet this understanding must include direct accounts of those most affected and who might not be heard otherwise, an undertaking facilitated by an advocacy perspective.

Ethical considerations

As Bogdan & Biklen (2003) note, the principles of *consent* and *protection of subjects from harm* (p. 43) are the two primary tenets which guide ethical research practice. Within these parameters, the well-being and cognizance of participants are essential (Canella & Lincoln, 2011; Christians, 2011; Denzin & Lincoln, 2011). This is particularly relevant when working

with groups who have traditionally been marginalized from research processes and decision-making, and disability researchers in particular have noted the possibility for abuse of the above-named principles when historical power imbalances in research relationships are not accounted for (Beazley et al, 1997; Bricher, 2000; Goodley & Moore, 2000). While a power differential did exist in this study between the ‘researcher’ and the ‘researched’, particularly in regards to my role as interpreter of participants’ experiences, steps were taken to ensure that the project was undertaken in an ethical manner.

First, ethical approval was sought and gained from the ethics approval committee at the supervising institution prior to embarking on the research project. Second, the project was explained in detail to all participants prior to their consent to ensure that they knew precisely what they would be agreeing to if they did indeed consent to participate in the project. This practice was repeated when participants met with me for their interview. All participants were asked to give informed written consent for participation in this study. In order to ensure that all participants fully understood what was being asked of them, the consent form was discussed in detail with each participant. A copy of the consent form was left with each participant. My contact information, as well as the contact information of my academic supervisor and for the university at which I am based was given to the participants with the consent form. The participants were informed that they could halt the interview if needed, and that they could demit themselves from the project at any time, including after the interview’s completion.

Interviews were conducted in a respectful manner. Assistants accompanied some participants as they desired. If at any point a participant needed to take a break during an interview, this request was obliged. All participants received a typed transcript of their interview in its entirety. Assistants who had accompanied a participant in the interview were notified when

the transcript was sent out, so that they could make themselves available to assist the participant in reading the transcript if necessary. Feedback and comments from participants in response to the transcribed interviews was welcomed. When the dissertation was nearing completion, summaries of the research findings were sent out to each group of participants. At that point, they were asked if they would like to see a complete copy either of the findings from their own group, or of all of the findings and analysis chapters.

Last, because of the personally investigative nature of this research, steps were taken to ensure participants would have access to support should they experience psychological or emotional suffering through the course of the project. Prior to embarking on the interviews, I had enlisted the support of several community agencies who agreed to provide psychological support and counselling should participants feel the need to further process their own narrative beyond the research setting (see Appendix A). All of the participants indicated that they had access to some kind of community support should the need to discuss the interview arise after its completion.

Participant confidentiality and privacy were respected throughout data collection and analysis procedures. At no time were participant names shared with other participants. Audio and paper data were securely stored in a locked cabinet in my home office. Recruitment and identifying information were stored and locked separately from research data. No names or other identifying features were used in the writing of the findings and analysis. Research data will be stored for one year after completion of the study, at which time it will be destroyed.

Sample

The sample for this study was derived using non-probabilistic techniques, a method which does not attempt to draw a sample that is “formally representative of [a] larger, well-

defined target population” (Palys, 1997, p. 135). Rather, I drew a purposive sample (Creswell, 2009; Palys, 1997), a sampling type which seeks out specific individuals because “they meet criterion for inclusion in the study” (Palys, 1997, p. 137). The reason for this acquisition method was the delicate nature of people’s personal experiences of institutionalization, both directly and indirectly, and the concurrent need for absolute respect for confidentiality when seeking people to participate in a study reflecting on those experiences. The phenomenon of institutionalization is, for many of those affected, a hidden, shameful, and painful history. In order to gain access to people’s personal accounts of that history, great care was taken to ensure participants were willing to be involved, that they came forward of their own accord, or that they were asked about their interest by someone who already knew of their experiences concerning institutionalization.

The inclusion criteria for this study fell into five categories: i) people with intellectual disabilities who were institutionalized at a government-run institution in Ontario after WWII, ii) parents of people who were institutionalized iii) siblings of people who were institutionalized iv) former staff who worked in government institutions during this time period and v) key informants, or people with a depth of knowledge and experience in the area of study.

Participants were garnered through a combination of ‘snowball’ sampling (Palys, 1997, p. 139), word of mouth, and making contact with specific organizations run for and by people with intellectual disabilities. Initially, two participants, both siblings of people who had been institutionalized, learned of the study through the public defense of my dissertation proposal and contacted me with requests to participate. From one of these participants, further contacts were made, including members of her own family (the first of several incidences of ‘snowball sampling’) from which I was able to elicit more participants. One participant was recruited via my fortuitous reading of something she had written about her own encounters with

institutionalization; her public account of her experiences gave me 'permission', so to speak, to contact her about participating in the study. Further, I contacted various agencies who work with or on behalf of people with intellectual disabilities within my immediate geographic area. These included the Toronto and Ontario Associations for Community Living, communal living settings for people with disabilities, and organizations which work for the inclusion of people with disabilities in schools and other public spaces. In these situations, I first contacted a supervisor or executive director, who considered my request, and who would then approach possible participants on my behalf. In this way, I did not ask people about their participation directly, but relied on those who already had an established and trustworthy relationship with the individual, and already knew about his or her experience of institutionalization. Interestingly, many of the survivors of institutionalization agreed to allow me to contact a sibling (or, in one case, two siblings) to ask if they would like to participate, indicating little hesitancy on the part of survivors to bring forward perspectives from other members of their families.

Participant confidentiality and privacy were respected throughout this process, and I remained committed to participant anonymity. Balancing anonymity with the need to locate participants did, however, make the recruitment process difficult, particularly when I contacted local agencies who might be able to put me in touch with people with disabilities who had lived in institutions. To respect people's privacy, people who worked at the agencies would ask individuals on my behalf, which sometimes resulted in lines of communication taking several weeks to complete, or not being completed at all. Some people who work with people with disabilities were concerned about the implications of my speaking with survivors or with their family members on their working relationships with these individuals and thus did not pursue further contact.

Most notably, I encountered difficulty when attempting to contact parents of people who had been institutionalized. Many parents from this generation have passed away, thus making the potential pool of people to interview much smaller. Further, I encountered what appeared to be protectiveness from some of the adult children of these elderly parents. Some of the grown children were understandably concerned about their parents engaging in a discussion which could invoke painful memories, and felt that this was a part of their lives which perhaps need not be discussed. This hesitancy, both from parents and their immediate contacts, is perhaps indicative of larger cultural assumptions regarding the phenomena that I set out to investigate. It seemed that the initial response of some parents and their adult children was grounded in the presumption that the social discourse around parents' decisions to institutionalize was a regrettable one that had had long-term negative effects on their children, and that I, as researcher, would be engaging with them from this perspective. Thus, the need to communicate my intentions clearly with participants, and parents in particular, became evident early on in the process, and I specified that my role was researcher, not judge. Moreover, I encountered some adult children (members of the sibling group) who were clear that they did not want me to conduct an interview with a surviving parent because of the relational strife which continued to exist within the family due to the experience of institutionalization. In accordance with these wishes, I did not approach these parents.

Last, it is important to note the impact of a class action lawsuit launched against the Ontario government by two institutional survivors on my ability to recruit participants for this study. Brought forward on behalf of all those who were institutionalized at Ontario's Schedule I facilities and for the mistreatment they suffered there, the lawsuit came to the fore while this research project was being conducted. Accordingly, some of the 'middle-people' with whom I

had contact in the hopes of finding participants reported that, particularly for parents, the timing of my study was not fortuitous; enough difficult memories had been stirred via stories emerging in the media and in court proceedings, and for some, further conversation was not an avenue they wished to take.

The difficulties in recruitment notwithstanding, my hope was to achieve both a breadth of reflection (through participation from multiple families), as well as depth (by participation of more than one person in the same family). Of the thirty-six participants, twenty families were included; within these twenty families, five had multiple representations. That is, two of the families had two participants (a parent and a sibling each), one family had three participants (two siblings and a survivor), and one family had four participants (two parents and two siblings). In all, those interviewed included nine survivors of institutionalization, eleven siblings, eight parents, four former staff, and four key informants. Details of all study participants, including their relationships with each other, are given in Appendices B to F.

While this is not a large sample, it meets the criteria for a qualitative study of this nature both because of the depth of the interviews conducted, and the delicate and painstaking nature of the recruitment process. Certain biases became evident in the sample, particularly concerning gender and class. In regards to gender, of nine survivors, three participants were women and six were men, thus giving those findings a male bias. However, the sibling, parent, and key informant groups were more heavily represented by female participants. In the sibling group, nine of the eleven participants were female; in the parent group, six of the eight participants were female; and in the key informant group, three of the four participants were female.

Accordingly, two issues arise. The first concerns the tendency, addressed in the literature, towards greater female representation in qualitative research (Polit & Beck, 2008).

Second, scholars suggest that gender representation in qualitative research is complicated by issues of “gender socialization and... social constructionism” (Affleck et al, 2013, p. 156), as well as men’s felt need to present an “essentially masculine self” (Schwalbe & Wolkomir, 2003, p. 56) in interview situations, a persona that might be particularly challenged by a topic which has the potential to evoke strong and sometimes difficult emotions. While these claims cannot be tested in this particular study, three men (all siblings of other participants) who were contacted for potential participation declined the invitation. Seven of the nine female siblings were willing and agreed immediately to participate. The fathers and brothers who participated in this project appeared significantly more composed and less emotionally distraught by the experience of institutionalization than did the mothers and sisters. As researcher, I suggest that these gender biases be taken into consideration when drawing themes from this study and from subsequent work, particularly those that address issues of power. That is, while findings suggest that, besides the direct survivors of institutions, women and girls seemed to suffer most from institutionalization processes, this must be tempered by the knowledge that there were fewer male participants, and that the men’s composure in the interview setting could be as attributable to a learned restraint from expressing difficult emotions with a stranger, as from a quantifiable emotional distance.

Further, the sample garnered for this project did suggest some class distinctions. For example, within the survivor group, five of the nine participants indicated that their families were situated in a lower socio-economic stratum. This was made clear by their references to the kind of work their fathers had (manual or factory), the kind of home they had while growing up (apartment or lower-class neighbourhood), and the resources available to their families. Four of these survivors referred specifically to the involvement of social welfare services in their family

home, which, it became clear during the interviews, played a role in their placement in an institution. The reverse, however, is true for the sibling and parent groups. That is, all eleven of the sibling participants identified as being raised in middle- to upper-class homes, and an identical demographic exists in the parent group.

Thus, an interesting dichotomy emerges, one which has already been iterated in the literature (McLaren, 1990; Simmons, 1982), and which is repeated in the findings here. That is, for many middle-upper class families in the era encapsulated by this study, the shame of having a child with an intellectual disability was a key motivating factor in their placement in an institution. Conversely, as Gleason (1997) and Strong-Boag (2011) have indicated, the intervention of social welfare professionals in the lives of postwar Canadian families also resulted in the placement of hundreds of children from lower-class homes in institutions for the ‘feble-minded’, understandable when one considers the ubiquitous conflation of lower intellectual capacity with lower socio-economic status throughout this time period, as described in Chapters Two and Three.

Accordingly, similar to the gender distinctions discussed above, themes drawn from the findings of this study must be tempered with an acknowledgement of the implications that social class would have had on family situations, familial decision-making, and understandings of disability. That is, while children growing up in middle-upper class homes might have understood their parents’ decision as one which stemmed from the embarrassment and shame of having a disabled child in the family, those from a lower socio-economic stratum might also acknowledge the role of social welfare interventions and the influence of social discourse concerning intellectual disability in their institutional placement. For the purposes of our

concerns here, therefore, it is important to acknowledge the influence that these emergent biases might have had on the themes which emerge from the findings.

Primary data collection: Interview process

At the outset, my intention was to conduct interviews until ‘saturation’ was reached. For the purposes of this research, saturation is defined as the point in data collection at which “no new data is emerging” (Corbin & Strauss, 2008, p. 143) or when specific themes and relationships between concepts consistently surface. While current postmodern assumptions might suggest that a true point of saturation is impossible to meet due to the infinite array of experiences held, even within one phenomenon, there is agreement within the research community that when themes begin to repeatedly emerge from the data and the researcher begins to hear overlaps between accounts, it is time to begin to draw analyses and conclusions.

Thirty-six semi-structured interviews were conducted for this research. Prior to and at the beginning of each interview, I explained the purpose of the project and what each participant’s involvement would entail. Each participant was reassured of the confidentiality of each interview, and was reminded that should they desire to remove themselves from the project, they could do so at any time, even after the interview was complete. Each participant received a written consent form, with details of the project and the scope of their responsibilities and rights as participants. For those participants who could not read, an oral version of the consent form was discussed with them to ensure that they fully understood the nature of the project and what was being asked of them. All participants signed the consent form.

The interviews were qualitative in nature, with guided questions (the interview guide is shown in Appendix G). While participants were encouraged to share experiences as they wished and to discuss issues important to them that were connected to the research topic, I did have pre-

established questions that were used to keep the conversation moving and to ensure that the most relevant areas of concern were discussed. The interviews lasted from between forty-five minutes to two and one-half hours. With participants' consent, all interviews except for one were audio recorded, with the interviewer taking supplementary hand-written notes. Twenty-three interviews were conducted in participants' homes; nine were conducted in an office setting, either at the participants' place of work or at the offices of the agency or community group with which some survivors were connected; one sibling conducted her interview in her parents' home; two conducted the interview at my home, and one took place in a restaurant. Five of the participants were accompanied by friends who provided some assistance to facilitate understanding between the interviewer and those being interviewed.

Transcription

As principal investigator, I undertook the transcription of each interview. While this was a time-consuming process, it ensured confidentiality of the research material, a condition to which I had agreed in the ethical considerations for this project. Only I was party to the conversations that took place, and each conversation was treated with the utmost confidentiality. Further, line by line transcription allowed intimate familiarity with the material, which facilitated the recognition of themes and patterns when they began to emerge.

A completed transcript was sent to each participant in the mail or was hand-delivered. For participants for whom reading is not a viable method of communication, the assistants who work with them were advised that transcripts had been sent, so that they could assist in reading and discussing it if the participant desired. All of the assistants notified me that the transcript had been received; however, none indicated to what extent the transcript was discussed with the participants. All participants were asked to notify me if they noticed any errors, if there was

anything they wanted added to the interview transcript, or if there was anything they wanted removed. Accordingly, some changes were made after the first draft of a transcript had been sent. For the most part, these consisted of spelling corrections to people's names or locations. Of the thirty-six participants, eleven (three of the survivors and eight of the siblings) offered more information after the initial transcript had been sent to them. In all of these eleven cases, participants offered more detail about their family history that had not emerged in the initial interview, information that on retrospect, they had felt relevant to the research concerns³.

Secondary data collection

Historical data was obtained at the Provincial Archives at York University. Searches were conducted on historical records of institutional facilities in order to obtain information about dates of construction and the numbers of residents in institutions during given time periods. Permission was obtained to look at some resident files from decades past; this provided a window into the conditions under which residents lived while housed at provincial institutions and shed light on the descriptors used in reference to people with intellectual disabilities from staff and persons with authority. Further, national and provincial statistics regarding the estimated numbers of people in the population designated as having an intellectual disability were examined in order to try and determine the extent to which families were choosing to institutionalize their children. The data obtained from secondary sources was used in Chapters One to Five of the dissertation in order to provide the historical, theoretical and contextual framework of the project.

Data analysis

Data analysis strategies for the primary data gathered through interviews were originally intended to follow a grounded theory approach. According to Creswell (2009), grounded theory

is “a strategy of inquiry in which the researcher derives a general, abstract theory of a process, action or interaction grounded in the views of participants” (p. 13). Grounded theory is suitable here as it allows for the development of “theoretical constructs” (Corbin & Strauss, 2008, p. 1) based on themes which emerge from participant narratives. Moreover, grounded theory permits flexibility in data collection and analysis (Charmaz, 2006, p. 2), adhering to “general principles and heuristic devices as opposed to formulaic rules” (ibid), appropriate due to the semi-structured nature of the interviews and the need to sometimes adjust their structure and format.

However, there were aspects of the methodology which did not completely adhere to a grounded theory approach. In its purest form, grounded theory involves “multiple stages of data collection and the refinement... of categories of information... [as well as] the constant comparison of data with emerging categories” (Creswell, 2009, p. 13). While themes were identified as they emerged from re-readings of the data, and these themes were refined as new information was added, the manner in which interviews were conducted did not necessarily allow for a “constant” assessment of data, nor were there multiple stages of data collection. Rather, interviews were conducted in sequence and transcribed as soon as possible afterwards, with the bulk of the analysis occurring after the interviews were completed. Despite not meeting all the criteria for grounded theory in an unadulterated sense, however, this research has benefitted from its principle of deriving theoretical constructs from the narratives and experiences of participants. For example, and as will be discussed in greater detail in Chapter Twelve and in the concluding remarks, one of the principle findings of this research concerns the constructed nature of intellectual disability, a finding which emerged directly from participant narratives, in particular, siblings’ understandings as children of the need for their brother or sister to be institutionalized.

Data analysis for this study generally followed the traditional route of re-reading transcribed interviews, reflection on the material, categorization, and coding in the search for emergent themes and patterns. Simply put, this process entailed the breaking down of vast amounts of transcribed material to provide a detailed understanding of peoples' experiences, followed by the building up of theoretical constructs or themes between and among the various groups by drawing linkages between them.

What became quickly apparent was the need to first identify emergent themes within each group separately before embarking on a broader analysis across all participant groups. This allowed the principal concerns of each group, both within and beyond the principal areas of investigation, to be brought forward. Analysis within each group always included reflection on 'family considerations', as this was the primary intention of the research. That is, priority was given to analysis of the reflections within each group on the impact that institutionalization had on families; in the cases of former staff and key informants, their observations and understandings of these processes, as opposed to direct experiences, were considered. This provided a fixed common point within and between each group from which some of the final conclusions could be drawn.

A second round of analysis allowed other themes to emerge within each group. These themes encapsulated an array of experiences, such as incidences of exclusion and abandonment (in the case of survivors), the maintenance of family narratives (in the case of siblings), and the desire to remain clear of categorizations of intellectual disability (in the case of parents). Within this range of experiences, however, thematic congruence between groups emerged. Congruency suggests large, underlying and unifying themes that exist around the phenomenon of institutionalization; these are addressed in the final chapters and address issues of power, the

construction of intellect, and family considerations. It is important to note, however, that while these fundamental themes co-existed between groups, they were expressed and experienced in radically different ways. Outlying or non-congruent themes, further, suggest that there were aspects of the experience that were independent of each other, reinforcing the idea that institutionalization was indeed experienced very differently between different groups of people. A most profound example here is the variances in experiences of institutionalization between those who lived there and those who worked there, a non-congruency that is explored in more detail in Chapter Ten.

Data validity and reliability

The *internal validity* of this study was ensured through constant re-assessment of my commitment to the purpose of the study, its relevance, my role, and the role of participants. The sharing of interview transcripts and summaries of the findings with participants and solicitation of their feedback assisted in this process, as they could verify the “truth value” (Creswell, 2009, p. 199) of the meanings I ascribed in my analysis. Adjustments to the data were made in accordance with participants’ requests. Professional evaluation was ongoing throughout the research process, as findings and analysis chapters were sent to the dissertation committee for feedback as they were completed. Finally, acknowledgement of my bias, as indicated in the opening paragraphs in this chapter, contributed to internal validity, by declaring its potential impact on interpretations and analysis.

Steps were also taken to ensure *external validity*. This was primarily accomplished by gathering information from five distinct groups of participants. This “triangulation” or the “convergence of several sources of data or perspectives or participants...adds validity to the study” (Creswell, 2009, p. 191). The key informants were particularly relevant here, as they

offered a broader and slightly removed perspective, adding context and depth to the narratives of other groups. Discrepant information was not left out of the analysis, as “contrary information add[s] to the credibility of the account” (ibid, p. 192). Further, the primary data as garnered through interviews with research participants was supplemented and validated by archival documents, including institutional records, official government material regarding institutions, and past media accounts. Moreover, the external validity of the study can be tested upon its completion by presenting the findings to other, non-participant groups of people who experienced institutionalization, in order to calibrate the results against others’ experiences.

The *reliability* of the study was assisted through a number of strategies designed to ensure consistency. As much as possible, interviews, while needing to respect the individual attributes of each participant and the distinct parameters of each group, followed a general, pre-determined, and consistent set of questions (See Appendix G). Care was taken to avoid shifts in terminology in the interview process, and in the parameters and definitions used in the analysis (Creswell, 2009). This was assisted by the constant calibration of data (ibid) with themes that had already been identified. Throughout, the reliability of transcriptions was assured via the input of study participants, who, as mentioned, provided feedback after receiving their copy. Several re-readings of the transcripts also ensured that there were no errors in the transcription of data.

Limitations

The study’s small sample size is one of its limitations, as it is difficult to generalize findings when a relatively small proportion of the total number of people who experienced institutionalization participated in the study. As discussed above in the section addressing sampling, potential limitations exist in the drawing of conclusions due to gender and class biases

in the sample obtained. Further, with a small sample, there is the danger of assuming representativeness from what might be a non-representative sample (Miles & Huberman, 1984, p. 230). Moreover, there is the danger that the research topic attracted “accessible and... intellectually responsive informants” (ibid, p. 231). As is often the case when relying on people and their spoken narratives as the primary research material, it is likely that the study attracted people who were more accessible (ibid), were able to follow through on an interview process, and who had already reflected on the phenomenon in question. Indeed, in the earliest stages of this research, I had hoped to include participants who have lived in institutions and do not possess verbal communication skills. My own limitations in my ability to communicate effectively without using verbal language prevented this from taking place, and it remains, as yet, an unexplored facet of research in this area. Further, the public face of this topic at the time during which the study took place, that is, media sympathy towards litigants in the class action lawsuit against the provincial government, could be seen to have skewed possible participants to those who were in agreement with the public discourse against institutions, thus potentially limiting the sample size even further. Despite the fact that the findings might not be completely generalizable due to the above factors, they remain valuable in terms of their narrative potency within the field of disability studies, in particular from a historical perspective.

Another limitation concerns the notion of memory. As this was a study which relied entirely on people’s recollection of events that occurred decades earlier and on the feelings that accompanied them, there was concern that the inability to recall accurately could limit the amount of data gathered and its reliability. One sibling was concerned that her mother’s deteriorating memory skills might affect her recollection of particular events and the emotions connected to them. From my perspective, this mother’s account of past events seemed clear, and

was consistent with her daughters' and husband's recollections. After some clarifying conversations with the daughter, it appeared that her concerns were primarily centred on the mother's relatively unabashed sharing, which the daughter attributed to the loss of some cognitive skills, and which did not paint a flattering portrait of the mother. While in this case, in the end, memory did not appear to play a pivotal role, the situation does suggest that memory can have an impact on research of this type, a concern which remains valid in qualitative studies with historical considerations (Mabry, 2002).

Further, as in all qualitative studies, there is the potential for the researcher's presence to bias the responses that participants provide (Creswell, 2009; Miles & Huberman, 1984). In this study, this was of concern with different groups for different reasons. First, for most of the participants in the survivor group, their approval from outside sources, in particular by those who hold decision-making power in their lives, frequently determines the quality of life to which they might have access. I was concerned that I might be perceived as someone with that kind of authority, that is, that participants might assess what they felt I wanted to hear and oblige accordingly. However, I need not have feared. From the first interview, it was evident that the dearth of opportunity to discuss their experiences over the past decades, and a willing listener, made participants ready to reflect on and share their experiences honestly and openly. Second, I was concerned that both parents and former staff might not share their opinions fully or honestly for fear of presenting an image that was not in agreement with the opinions being expressed in popular discourse at the time. However, members of both these groups appeared willing to defend their support of institutions (if that was their stance), perhaps in an effort to present what they felt was a counterweight to the stories that were being publicly acknowledged. Clearly they

saw in me an opportunity to present the ‘other side of the story’, in contrast to the predominant media presentation.

In order to work counter to some of the limitations expressed above, I consistently assumed a neutral stance in the interviews to facilitate participation from all groups and to encourage people to share without fear of being evaluated. Despite evidence of my bias, indicated by my interest in the topic, by the nature of my programme of study, and even by the working title of my dissertation, participants in all groups appeared willing to share experiences with me in an honest and straight-forward manner.

Time frame for the study

The dissertation proposal was approved in April, 2012. Ethics approval from the supervising institution was received in June 2012. Research interviews took place over a fourteen-month period, from August 2012 until October 2013. Interviews were transcribed as soon as possible afterwards. Research at the Archives of Ontario occurred at various points during this period. The writing of the dissertation also took place throughout this period. The first complete draft of the dissertation was sent to the dissertation committee in February 2014.

Setting

Research interviews took place where it was most convenient for participants; therefore, I travelled to various parts of the province to facilitate these meetings. Fortunately, participation was elicited from people who had lived in or had family who had lived in all three of the large Schedule One facilities in Ontario—Huron, Rideau, and Southwestern Regional Centres—thus covering the huge geographic ‘triangle’ that these three principle institutions created. Despite the geographic reach of institutional care in Ontario, it was striking that there were common points

of experience within and between all groups, regardless with which institution they were connected.

Conclusion

This chapter has provided an overview of the steps taken throughout the research process in order to elicit participants, conduct interviews for the primary data, gain secondary information, and analyse the data. The five chapters which follow present the principal findings from each of the five groups of participants. Following that, a summative analysis and conclusion is presented.

Chapter Seven: Findings, Survivors

Introduction

“It wrecked me sadly” (*Calvin, survivor, Rideau Regional Centre*)¹

Nine survivors of institutions were interviewed at length for this research project. Of the nine, six were men and three were women. All of the survivors were institutionalized in government-run institutions in Ontario during the time period specified in the research parameters, the earliest admission being in 1948, and the most recent 1965. The number of years that participants lived in institutions ranged from nine years to approximately thirty-five years. All of the survivors spoke independently of their experiences. Indeed, I was moved by the unflinching honesty and rigour with which they recounted the narratives of their decades spent under institutional care. It is clear that all of the survivors have reflected on their experiences in such a way as to raise significant questions about socio-political and cultural meanings attached to disability as expressed through arrangements made for their lives, and have addressed fundamental questions about the meaning of their lives within modern society.

Not surprisingly, the narratives shared by survivors of institutions about their institutional experiences and the impact this had on their lives and their relationships with other family members were marked primarily by confusion, sadness and loss. All of the survivors described this period of their lives as an unhappy one during which attempts to mark their identities as ‘other’ requiring sequestering from the rest of society were solidified. Moreover, reflection on this period has brought up fundamental questions regarding their sense of self and the meaning and value of their lives. The most persistent theme articulated by all survivors was simply—*I did not like it there. I like it much better here.*

The discussion which follows begins by addressing the primary concerns of this research, that is, the impact of institutionalization on family relationships and understandings of disability. The discussion then moves to address other themes which emerged as survivors spoke about their experiences. First, participants who were institutionalized describe experiences of profound exclusion, both from regular engagement in everyday life, including the rights, responsibilities, and freedoms to which all persons are entitled, and from the more subtle arenas of public and private discourse which played a role in decisions regarding their future. Reflections from survivors suggest that exclusionary practices were based on the assumption that the needs and concerns of people with intellectual disabilities were considered unimportant and irrelevant due to their formulation by people assumed to have some level of intellectual incapacity. Comments from survivors also indicate that exclusion must be examined within a human rights framework which exposes the prioritizing of the needs and concerns of people in authority and the family as a whole, at the expense of the needs and desires of people with intellectual disabilities. Second, all survivors referred to a sense of abandonment by their families in regards to their placements in institutions. Each survivor expressed bewilderment and struggled with the lack of clarity and explanation regarding *why* he or she had been sent to live in an institution. This experience of abandonment, articulated by the oft-repeated comment “I don’t know why my family sent me there”, points beyond culturally-acceptable yet essentially perfunctory reasons, to fundamental ontological concerns regarding the meaning and value of individual lives, a subject with which survivors of institutionalization have had to grapple throughout their lives in light of their own histories. The chapter concludes with examples of survivor accounts of their actual experiences of institutional life. While not a central focus of this research, it is felt that reflection on the direct and lived experiences of institutional survivors is

essential to a thorough understanding of the phenomenon of institutionalization as a whole and its impact on family relationships and understanding of disability. In the following pages, I examine these issues from the perspective of the participants in an attempt to understand the phenomenology of their experiences, and subsequently to provide broader analyses which contribute to the project as a whole.

Family relationships and understandings of disability

One of the principle goals of this research is to investigate the impact of institutionalization on family relationships and understandings of disability. Findings suggest that survivors' experiences in this area range from interruption and disruption in family relationships, to ones of extreme brokenness. All of the survivors stated that relationships with their families were, at the very least, strained and unnatural because of the intermittent and infrequent nature of their contact, and because of the inability to interact in the normal, day-to-day manner of regular family life. This was true even for the five participants whose families came to visit on a somewhat regular basis. The rigidity of the institutional setting, the limits placed on families regarding how often and when they could come and visit their family member, and the real and metaphorical distance that institutions created within families disallowed the development of the depth of relationship that would be considered normal between parents, children, and siblings. Quentin, whose parents came to visit him every two weeks, stated that the visits were difficult: "the thing was it was too short. They just...you had so many things you wanted to say, and not enough time to say it in". In all of the cases described, visits happened in a designated visitors' space, thus locating the connection in a false, controlled site not reflective of what rituals and space that the institutionalized individual might have

attempted to lay claim to. Thus, temporally and spatially, the institution maintained control over the extent of the relationships that families endeavoured to maintain.

Further, all of the survivors whose families did visit remarked upon the distinction within their families regarding who came. Visits were primarily from their parents; in five cases, survivors were not visited by a brother or sister for the duration of their institutionalization. Thus, for decades, the majority of the siblings had no contact with each other. The implications of this were enormous in regards to the level of understanding siblings developed of each other, and on how they related with each other later in life, when the forced distancing of institutionalization became the forced reckoning, through deinstitutionalization, of a familial bond, untended for decades. One survivor, André, spoke of his parents' desire to absolve his siblings of any responsibility from maintaining contact with him while institutionalized, as his mother felt it was a responsibility that siblings should not be obliged to carry. This protectionist stance exhibited by many of the parents towards the non-institutionalized siblings suggests a tacit agreement with predominant discourse around 'normal' family functioning. The parents' desire to ensure a 'healthy' upbringing of the non-institutionalized children included a forced distancing between them and the 'abnormal' child who lived in a place with contaminative potential. Most sadly, survivors were, for the most part, unable to articulate why their siblings did not come; to them, the decades of distance reinforced survivors' engrained self-knowledge as someone undeserving of the affection and attention of others. Further, three of the survivors, Gord, Hilary, and Quentin, reported that they each had an older brother who came to visit many years later, once the brother had left the family home, and had re-established contact with their institutionalized brother or sister (Gord and Hilary's older brothers are both participants in the sibling group). Despite the small sample size, the observation that only brothers attempted to re-

establish contact with an institutionalized sibling while he or she remained incarcerated is of interest. While far from conclusive, it suggests that some time- and gender-specific discourse could have been at play which simultaneously excused girls and women from taking steps into what might have seemed a dark and dangerous place—both the physical manifestation of the institution, and the unknown tangibles of relationship with a ‘stranger’—and allowed boys and men to manage those relationships in ways that they directed, even if that meant venturing into a previously hidden part of the family story. These differences might also indicate an assumption, conscious or not, that older males might eventually assume the role of head of the family, thus instilling some sense of responsibility towards their institutionalized sibling. Alternatively, these three scenarios could simply suggest that some siblings had greater concern for their institutionalized sibling than others. In two of these cases, survivors noted that their absent sisters re-appeared more consistently once they had left the institution and were living in the community.

Six of the survivors stated that the damage caused to family relationships went beyond the disruption described above, and resulted in a brokenness which, for the most part, has remained, years after leaving the institution. In the most extreme cases, some survivors lost contact with their families altogether. For example, Walt, who had been placed in foster care prior to going to an institution, noted “it was like I had disappeared from the planet. No-one knew where I was, even my family”. This man was re-united with his mother and brother a full eighteen years after being discharged from the institution. Quentin also spoke of his mother’s lack of knowledge that he had been discharged from the facility; he noted that it was two years after he was discharged that his mother finally learned that he was “out”. While this circumstance can most certainly be blamed in part on the institution and its lack of adequate

communication with the family, breakage between family members as a result of long absences no doubt also played a role here.. Finally, two of the women spoke of the ongoing brokenness and difficulty that exists in their families, a direct result of their being sent to live in an institution. Anna, in reference to her attempts to forge relationships with family members practically lost to her for decades while institutionalized, stated, “it [the rejection] happened too many times growing up, and I couldn’t bond with any of them.... I quit trying”. Thus, while all survivors noted some level of disruption and interruption in what would be considered normal family relationships, some experienced extremes of brokenness, to the point of not knowing the whereabouts of their own families.

Notable within this sad assessment, however, is that survivors, save for the two women mentioned above who expressed a significant amount of anger, do not blame their families for their institutionalization and their subsequent long absences from the family home. Most of the survivors demonstrated an incredible depth of understanding and forgiveness towards their families in regards to their placement, although they were troubled, often deeply, by the seeming lack of sound explanation for their decision, which will be dealt with in greater detail below. Indeed, while not consistently articulated by each participant, there were indications that survivors detected the stronger influence of outside authorities in the decision to institutionalize, and that their parents were not necessarily the key players. André recalled, “there was a nurse talking to my mum and dad... and I said No...yeah, a decision for me. I didn’t like it”. This observation—that external influences such as intervention from social welfare services might have played a role in families’ decisions to institutionalize a child—supports indications that families of a lower socio-economic status, a stratum within which five of the survivors indicated their families belonged, were more likely to be coerced into institutional placement than their

wealthier counterparts. That is, and as we shall see in the following chapter, families from a higher socio-economic stratum were more likely to place their child due to lifestyle and class considerations, whereas families from a lower stratum were more likely to have been strongly encouraged to do so by outside authorities. For our purposes here, however, it is important to note that for the most part, survivors did not actively blame their families, although they remained confused about their parents' reasoning and could not adequately explain to themselves or others how their parents arrived at this decision.

The third principle observation from survivors regarding family relationships concerns families' interpretations and understandings of disability. Of note, all but two of the survivors stated that their parents believed that the institution would be a better place for them, an observation that was indeed confirmed when research was conducted with parents. Calvin stated, "[my father] said that he felt, personally, that I would be safer there...but I wasn't too keen..." Quentin stated "Dad saw it as the best place for me". Eventually, this was a difficult truth for many of the survivors to acknowledge—that their parents' reasoning for institutionalizing them, if safety and care were their priorities, was faulty—and that they had indeed encountered much more harm than anyone could have imagined. This was a double blow: first, the lived reality of an abusive institutional environment, and second, acknowledging their parents' misguided decision-making and limitations.

Four of the survivors acknowledged that their families or the Children's Aid Society, misread their abilities and behaviours, and that this played a key role in their admission to custodial care. Irene stated, "they made me out to be worse than I really was". These four survivors (Quentin, Walt, Anna and Irene), all of whom are now active in the self-advocacy movement, acknowledged that their families either did not have the skills and resources required

to care for them, or did not act as advocates on their behalf and resist recommendations for institutional care in situations where a life at home might have been possible. All of these cases were, notably, within families of a lower socio-economic status, suggesting a conflation between socio-economic circumstances and recommendations for custodial care. Survivors' statements suggest that seemingly substandard living conditions contributed to the decisions of authorities, and in these situations, families felt compelled to acquiesce to the stance of authorities, as it constituted a discourse which some families felt unable to contest. Thus, some of the survivors astutely observed that rather than their own seeming lack of ability being the principal reason for placement, cultural interpretations of intellectual disability, as well as their families' inability to advocate on their behalf against those interpretations, were the principal driving influences.

Walt in particular provided an insightful explanation of the government's construction of the intellectual incapacity of many of those they deemed disabled, and the tenuous physical and political structures that were used to define and contain them. He noted,

I don't know why I went there. Because I was a normal person before I went there, and it's like...I was locked up in there... it was disgusting how the government talked about us. Retarded this, mental this, moron this, retarded this.

He went on:

I want to talk about something really interesting. My IQ was 78, so why did I go to [institution]? It's right in my records—it says my IQ was 78, 80, something like that.... there it is—IQ of 56, IQ 78, IQ of 63. They said—*mild*

moron range of intelligence, borderline range. And I say
to the government—shame on them. Giving us
labels...these were labels that weren't even true...And me,
I was normal. But we were all normal....But nobody
wanted us. So they locked us up. That's the only reason I
can think of.

This survivor, who is in possession of his hospital records, is wholly cognizant of the authoritarian construction of his 'lesser' and constantly shifting intelligence, and of the government's thinly-veiled desire to segregate those deemed worthless and unwanted.

One last notable finding from this section stems from my role as researcher and observer. While listening to survivors' stories, I became aware of how much they did *not* know of their families' lives, of the family life that existed and carried on in their absence. This was made evident in two ways. First, survivors do not really know what their families thought of their absence, nor do they know about the processing that their families must have undergone in order to come to terms (or not) with their placement in an institution. That is, survivors' comments revolved around the depth of loss and rejection that they themselves incurred, and of their ongoing work to reconcile two co-existent truths—that despite the inherent worth and dignity of their lives, they were, nonetheless, abandoned. Rather than attempting to frame and understand the meaning of their incarceration from the perspective of their families—and why should they?—survivors indicated that the primary emotional work in their lives remains coming to terms with their placement in an institution. All of the survivors were well able to articulate the grief that they have encountered as a result of institutionalization. All indicated that institutionalization was a period in their lives that they would rather not have lived, and that their

lives now are preferable to their time spent there. Accordingly, survivors' concerns do not lie with how their families interpreted their absence nor with the changes that their families' understandings of disability might have undergone over the years, but rather with how this period in their own lives has so profoundly affected them, and how they will continue to come to terms with it.

Second, as listener, I became aware that survivors did indeed miss out on a great deal of what went on in the family home, and that for the most part, they were not aware of those developments. For example, and I draw on the findings from sibling and parent interviews here to better illustrate my point, one family (of which both parents and two siblings participated in this research), explained that they had two distinct Christmas celebrations: one, several days or weeks prior to Christmas with their daughter who had been institutionalized, who came home for that celebration; the second, a celebration on Christmas day with the extended family to which their daughter was not included. The first one they called "Nora's Christmas", thus distinguishing it from the actual Christmas, marking its distinction as the celebration which included the generally absent family member. While the demarcation between these two celebrations is a difficult enough reminder of the delineation between people with intellectual disabilities and those without, what is more poignant (and I make an educated guess here, as Nora is no longer alive) is Nora's not experiencing, and never knowing the family's other, 'real' Christmas celebrations. While this is a gap of which Nora might not have been aware, for the distinction between the two celebrations might never have been explained to her, the gap continued to exist and was obviously maintained at some expense—the investment in organizing two Christmases is significant, but the need to maintain the demarcation must have been seen as worthwhile—and it disallowed one family member from participating in the full extent of a

family's traditions. Thus, there existed a hole in Nora's understanding of her family, like an unnamed piece of her story that she was not allowed to partake in and perhaps even be cognizant of.

In another example, two men, André and Quentin spoke of attending their fathers' funerals while they were living in an institution. Neither of them was able to attend to their fathers, nor to visit with them in any way in the days and weeks leading up to their deaths. Rather, they marked their fathers' deaths with the perfunctory one-day experience of attending a funeral, with an immediate return to the institution. Quentin said, "that was the only time I got to go home. I didn't go home for visits for eighteen years. The only time I went home was when my father died". (It is worth noting that this gentleman only saw his sister once in his two decades in an institution, at his father's funeral). André also noted that the only time he went home from the institution in his twenty years there was in order to attend his father's funeral. Similar to the previous example, one can presume that there was much that these men must have missed in the deaths of their fathers, and indeed during their lives prior to that, including partaking of any insights their fathers might have shared, and at the end, the opportunity to say good-bye. This removal from the 'normal' cycles of family life, even in more intense moments such as family celebrations and deaths, has meant that survivors continue to live with spaces in their family stories that will never be filled on account of their own absence from the family home. It is these gaps that contribute to some of the painful points in family relationships with which several of the survivors continue to struggle.

Exclusion

One of the principal themes articulated by institutional survivors is the experience of exclusion. By exclusion, I draw from Young's (1990) analysis of marginalization to denote the

phenomenon of the expulsion of “whole categories of people... from useful participation in social life” (p. 53). This exclusion was apparent in survivors’ prohibition from practical rituals and milestones of everyday life, and from communal spaces within which mainstream society functions, relates, and creates culture (Dorn, 1999). The profundity of the loss and grief experienced via cultural and social exclusions, albeit seemingly small, cannot be overstated. André, who came from a family that frequently made music together, spoke of his acute sense of loss from being prevented from doing that for more than two decades:

I was the real [singer], because I love it. Ever since I was a little kid....Yes, I’m still singing... because I want to because it’s better for me. Because it gives me a chance to think about that, and do the singing, what you want. Because it’s better for everybody to listen to... this is the best thing you could do... my father was playing the piano and banjo, guitar, the big bass, and plays the violin and plays the piano... play music, play piano, play cards, oh boy.

He went on to explain that, while institutionalized, rather than directing his energy and talent into the music-making that had brought meaning to his life, he had to focus rather on avoiding becoming caught in the negative energy and violence around him:

They fight in the morning, the afternoon, and night. That’s too much! ... I can’t, I can’t let that going on. I agree to get out of it, and get away from it... ‘Cuz I don’t want that happen to me. No way.

Thus, an important piece of this man's life was simply truncated when he entered the rambling bureaucratic mechanisms of the institution, a loss that was most likely unknown to anyone but himself.

There are countless examples of survivors' experiences of exclusion from the minutiae of social and cultural practices. All of the survivors, when asked, stated that their birthdays were never celebrated in the institution. One man did not even know when his actual birthday is. Hilary noted, "They never let me go outside. They never let me have my knitting. I used to stay inside every day, and sit in my room". Bob spoke of the taken-for-granted pleasure he has now in going to the video store, choosing a movie for himself and watching it at a time that suits his schedule, absolutely opposite to the institutional experience of being allowed only to stare at a TV perched high above the room, fixed at a station that may not be anyone's preference. All of the survivors, without being pressed, spoke about the overwhelmingly negative experience of institutional meals. In the institutions, meals were generally scheduled time slots for residents to obtain nutrition and nothing more. Quentin, who worked in the stores department at the institution at which he lived, stated, "The whole institution was in the stores department. So, I saw what food went out, why we were eating like pigs—the pigs ate better than we did". Although the above are small, concrete, and seemingly insignificant examples—undoubtedly, the importance of knitting to one resident would have been easily lost in the more pressing concerns of keeping the huge machinations of the institution running—they indicate the extent of the forced removal of meaningful praxis from people's lives. Bearing in mind the silence with which most residents would have held the knowledge of the rituals dear to them, there are undoubtedly infinite examples of survivors feeling a sense of exclusion from practices with which they had engaged prior to entering the institution.

At a more abstract level, survivors spoke of their exclusion from all arenas of discussion concerning their future. Overwhelmingly, the sense that emerges from survivors' comments is that they were disallowed from contributing to what Runté and Mills (2006) call primary discourses (p. 695), those avenues of power and decision-making that had a direct influence on their lives. Typical of the presumptions of the era in regards to the value and relevance of the concerns of both children and people with disabilities, survivors were relegated to positions of submission to the more prevalent and seemingly more valuable discourse articulated by people of authority, including parents or medical professionals. Those survivors who were old enough to remember the time period surrounding their admission to the institution also note that their input towards crucial decisions about their future was not considered. Calvin spoke of the conversation he had with his father soon after his mother had died, in which his father informed him that he would soon be leaving home to live at a large institution, two hours' drive away. While Calvin acknowledges that he was at least given warning about the impending move, he also remembers being confused and anxious, and remains at a loss when attempting to explain why his father felt this was necessary. This was a recurring theme in the survivor group; as will be discussed below, few of the other survivors recalled any conversation in the family home prior to their leaving, nor do they feel that adequate, or even attempted, explanations were given.

Limitations on self-determination are an example of domination, well-embedded in the super-structures of modern life and expressed via relationships that exert power (Young, 1990, pp. 31-37). Moreover, the exclusion being discussed here reveals a fundamental problematic concerning people with intellectual disabilities in the prioritization of the opinion of experts or of those in positions of authority over those of the people for whom these decisions will have the greatest impact. As Irene noted, "we were not allowed to have an opinion". From a historical

perspective, legal frameworks which ensure that decisions made on behalf of people with intellectual disabilities are done with the person's best interest in mind (Rioux, 2003) were not, despite the ratification of the UNDRH in 1948, yet consistently implemented in regards to people with disabilities during this time period (Koh & Gostin, 2003). Indeed, in the post WWII era, hegemonies of patriarchal authority remained firm features in the familial landscape, which meant that "companion" or "secondary" discourses (Runté & Mills, 2006, p. 700) within which women, children, people with disabilities, and others of marginal status would have been relegated did not carry equal authority within decision-making arenas (Young, 1990). The Gramscian notion of secondary discourses which lie parallel to and yet are essentially impotent beside hegemonies of power and knowledge (Sim & Van Loon, 2004) was the norm at the time in regards to certain segments of the population, and there were few expectations that people with intellectual disabilities would have anything meaningful or reasonable to contribute to decisions regarding their own future. When asked about the time at home just prior to institutionalization, survivors stated that they were either not consulted, or, if very young, were not adequately informed about the major shift that was about to happen. Anna spoke of her family's positive portrayal of the institution prior to her arrival there, and her own excitement at what she interpreted as an adventure:

I took the nurse by the hand, because I was all excited... I remember my parents said it was a hospital, and I pictured in my mind as a little girl, that it would have doctors and nurses all the time. But it wasn't like that. It was like a jail without bars.

For survivors, the lack of discussion concerning their immediate future remains a void, an uninformed space in their memory and understanding of the reasons why they ended up in an institution.

Moreover, indifference towards the contributions of people with intellectual disabilities relies on the assumption that an individual's 'incompetence' invalidates his or her ideas and opinions (Levitz, 2003; Mosoff, 2000; Stefan, 1993). Decisions concerning people with intellectual disabilities have historically been made on the presumption that such individuals possess a fundamental incompetence in regards to decisions which include their own care and the future direction of their lives (Ward & Stewart, 2008). This presumption of the essential superiority of intellect, which has been defended, often contentiously, by scholars in the humanities and social sciences (see, for example, Harris, 2002, and Singer, 2011), despite postmodern claims regarding the non-essentialist and constructivist nature of intellect, has been and continues to be a key limiting factor in the lives of people identified as having intellectual disabilities (Enns, 1999; Marzano-Parisoli, 2001; Rioux et al., 2013), and has played a significant role in their placement in long-term, segregated institutions. Some of the survivors in this study exposed the prioritizing of intellect in regards to assumptions which led to their institutionalization: "My family called me retarded... I got shoved away", Anna noted. Irene stated what she believed people in authority thought of her: "Oh, you're retarded; nobody's going to listen to you or believe you".

Further, the exclusions discussed above are indicative of prohibitions to basic precepts of human rights which were otherwise being enacted during this time period, yet remained unavailable and indeed unconsidered in regards to people with disabilities. In particular, as discussed in Chapter Five, the individual rights of people with disabilities as human beings and

equal members within their family and community went unrecognized within the politicized context of protecting the family as a cultural institution. The prioritizing of the family at the expense of the needs and desires of the family member with a disability inevitably contributed to the ongoing failure to recognize people's individual rights, and to the ubiquitous belief that institutionalization was an acceptable and indeed, often necessary, practice (Ward & Stewart, 2008).

This reveals a fundamental philosophical tension which remains in current cultural discourse between frameworks which emphasise the needs and concerns of the individual, and those which demand the precedence of 'the common good' (McLaren, 1990; Thomas, 2002). Although Simmons (1982) refers to the upswing in concern for human rights at the conclusion of the Second World War and the resultant calls for more humane care for people with disabilities, including deinstitutionalization, significant conflict around how far these rights should extend to people deemed less capable remained, particularly when the granting of such rights was seen as a threat to the larger population as a whole. Indeed, as previous chapters have indicated, arguments which favoured the protection of the 'public' from the dangers of the 'feeble-minded' over compassionate and community-based care for people with intellectual disabilities were fundamental to the development and continuation of long-term custodial institutions (Radford, 1991; Radford & Park, 1993a). Walt, who has gained access to all of his hospital and institutional records, recognized the implicit connections between the state's assessment of his mothers' capabilities, her subsequent threat to the community as a whole, and his own institutionalization. He reads from state documents: "*The child was born out of wedlock to a mother who is a mentally retarded moron. She was stressed and her husband deserted her. The boy has been a ward of the Children's Aid Society since age four and a half*". He adds, "My

foster mother thought that it might be better if I was institutionalized”. His documents reference ubiquitous concerns regarding the potentially deleterious effects of allowing people with disabilities to mix with the rest of the population. Thus, despite gradual increases in universal standards for human rights during this time period, people with intellectual disabilities remained less valuable and less deserving of the rights and responsibilities inherent to these standards.

While details of some of the human rights abuses that survivors endured while living in the institution will be discussed in a later section, it is important to note at this point that several survivors made the connection between those indignities and their exclusion from the fundamental rights deserving of every person. Anna stated, “We weren’t allowed to talk back. We had no rights. We weren’t allowed to think for ourselves”. Irene said: “Even the prisoners got treated better than we did”. Walt sums this up as a complete rejection from society: “They locked [us up]. Nobody wanted us in the society. That’s what we felt. Nobody wanted us, so they locked us up”. Moreover, he was aware that his incarceration was not standard practice for those considered non-disabled—“What did I do wrong? It was like I was locked up in prison, and put there against my will”. In sum, survivors describe exclusion from both the “traditions and meanings” that constitute cultural practice within broader society (Young, 1990, p. 86), and from fundamental precepts of human dignity, that is, exclusion from an acceptable, dignified, and fundamentally dignified way of life.

Abandonment

“They looked at me like I was a monster. It was abandonment and rejection” (*Anna, in reference to her family*).

Within the context of this research, interviews reveal that the experience of abandonment remains a tangible and painful thread in the lives of people with intellectual

disabilities, in these cases, specifically experienced within the parameters of family. The social location through which survivors experienced their most overwhelming sense of loss and rejection came not from the strictures of the institution, whose limits and regimentation are undeniable and will be discussed in a later section, but via their removal and absence from their own families, the principal site of one's formation as a relational individual with a place of belonging. When asked about their family's decision to place them in an institution, participants described simultaneous feelings of rejection and longing for those who had sent them away.

For survivors, abandonment was the overriding emotional characterization of their experiences of institutionalization, most painfully enacted the moment they realized they were being left behind. All survivors spoke poignantly about the moment at which they first fully understood that they were, essentially, being deserted by their families, often at the door of the institution, and overwhelmingly as children. André recalls

I was not happy at all. I started to cry. I held back tears, and I didn't know what to do, and I didn't like it. Said good-bye, and after that, I didn't know what to do with it.

Anna described her incredulity when she realized that her family was not going to stay with her, as she had understood:

I honestly thought that they were going too. I assumed that Mum and Dad would at least stay with me. As a little girl, I didn't understand. They *left* me. They abandoned me... I didn't think I'd ever see them again. I was scared, being left with strangers.

Walt described a profound experience of abandonment, in which he felt that he had been completely rejected from the world. He stated, “when I went to [the institution], it was like I disappeared from the planet. No-one knew where I was, not even my family”.

One of the principal sources of the sense of abandonment as experienced by survivors is the knowledge that their family, who, until that point, had been the only people in the world upon whom they could rely, had chosen willfully (or under duress in some cases) to remove them from the home. This was exacerbated, moreover, by the vacuum of knowledge surrounding any justification the family might have used for this decision. Of the nine survivors interviewed for this study, five clearly stated that they did not know why they had been sent to an institution, that their family had provided no explanation, and that there had been no discussion. As will be discussed in a later section, survivors’ desire to know precisely why their parents had decided to place them in an institution goes beyond perfunctory and practical explanations, and touches on deeper questions regarding the value and meaning of their lives, particularly in regards to their meaning relative to other brothers and sisters. Of those four who were given some information prior to their placement, Calvin stated that his father had taken him to the institution after his mother died, indicating that it was too much to care for him and his brother as a single father. Another two, Quentin and Anna, stated that their families believed that the institution would ‘cure’ them of their disabilities. Quentin, who went to the institution at the age of twenty recalled,

This was when I was still at home. And we called the
institution. And they said—*Oh, they could cure my epilepsy.*
Sure, my epilepsy, with medication. Well, I swallowed that
line of s---, went into the institution... And I became a

number on a piece of paper that was lost... So, this piece of paper became miraculously lost for eighteen years.

Anna referred repeatedly both to her family's labelling of her as 'retarded' and to the disappointment her mother expressed each time she saw her after her admission to the institution for its apparent failure to eradicate all evidence of her disability. She said:

I was always excited for them to come and see me. But Mum would act disappointed because I didn't become normal. They thought that the institution was going to make me normal, but it didn't make me normal.

Both of these experiences intensified these survivors' feeling of abandonment, for it appeared that the ongoing presence of their 'disability', however that was defined, drew them deeper and deeper into the confines of the institution, and further away from any possible reconnection with their family. Quentin and Anna, who might have gone to the institution under an auspice of 'cure', remained in an institution for eighteen and thirteen years, respectively.

Irene referred to her experience of absolute chaos and lack of control around her admission to the institution, and the scarcity of information regarding processes which led her there. Her family was absorbed into the care of the state while she was very young, and it seems that there was no discussion at any level within the family regarding ongoing care of the children, as many were sent away to institutional care. In this heart-wrenching example of the sense of rootlessness and rejection both by and of the family (in this case, facilitated by the state), Irene spoke of meeting, for the first time, some of her siblings at the institution where she had been sent.

Irene: I didn't believe she was my sister at first, because somebody mentioned that my sister was here or something like that... I thought I only had one sister, Lily, because that's all my family would talk about, was my one sister Lily. They never said anything about Kelly.

Madeline: So, you didn't know she was your sister?

Irene: No.

Madeline: Until somebody told you, and she was already living there.

Irene: Yeah... I finally accepted her as my sister, because I didn't know she was my sister.

Thus, in this family, several of the children were doubly abandoned, both by their own family, and by the state-sanctioned care which had been designed to 'protect' them from their family's 'deficiencies' and yet had contributed to the brokenness experienced by the children absorbed into its care.

In a similar vein, four of the nine participants identified abandonment as a practice which extended beyond the limits of their own families. These four survivors identified their desertion by the provincial government, which had not acted in their best interests but rather had acted principally to ensure the propagation of a long-accepted method of dealing with people with intellectual differences. Walt, for example, described learning of the government's awareness of the extent of questionable practices in provincial institutions:

Yeah, the government knew. And I was so upset inside. I was overwhelmed to hear—the government knew about this? And

they didn't do nothing about it? And so now, they want to wash their hands, just wash their hands and say—*No responsibility on us...* They took away our vocation, they took away our dreams, our hopes, everything. And what did they give us? They gave us nightmares. And I say to the government—*Shame on them!*... They knew what that word meant. They know what 'retarded' is... these people knew what they were saying and doing. Because if they didn't, why would they keep it a secret then?

Gord, while he did not comment specifically on his own personal experience of abandonment, remarked that he noted it around him via the care, or lack thereof, being received by some of the residents. He revealed:

I don't like Dr. _____, after what he did to the patients, letting them pass away... He tells a nurse to lie. He said—*the patients will be alright...* That's why one nurse said they didn't want him for a doctor after what he did in Orillia. Oh, that was terrible, letting them pass away.

Thus, for Gord, the full extent of neglect was enacted around him, almost certainly adding to his own experience of abandonment and uncertainty as a resident under the same levers of authority, in the same location, with the same kind of care.

The theme of abandonment as articulated by the survivors in this study are perhaps better understood by contextualizing them within broader theories of rejection which address abandonment both as a personal, negative, and emotionally-fraught experience, and as a systemic

practice which upholds societal precepts around normativity and acceptability. While the abandonment experienced by people with intellectual disabilities who participated in this project was a real and immediate phenomenon with profound and lasting effects, it can also be analysed through a critical lens which acknowledges the relevance of social and political movements, the advancement of capitalist societies, the progression of modernity, and processes of alienation and abandonment which resulted.

For example, the theoretical and historical analyses of Kristeva (1982) and Douglas (1966), as discussed in previous chapters, suggest that abandonment can be contextualized within a broader framework which examines the maintenance of societal norms. Kristeva and Douglas oblige us to look beyond survivors' phenomenological reflections, which reveal the real, intimate, and painful aspects of rejection, and to examine abandonment as a general practice within which modernist theories of progress are implicated. Kristeva refers to abjection as the process of rejecting and removing that which "disturbs identity, system, order" (p. 4), and of barring transgressions which threaten the larger group's moral and social fibre (p. 17). Kristeva notes the assumed priority of abjection in order to uphold the essential components of a productive, orderly, and modern society, wherein the abject are "jettisoned out of that boundary" (p. 69) when they threaten the progress of the group as a whole. Douglas, furthermore, suggests that rituals to deal with "matter out of place" (James, as cited in Douglas, p. 35) are ongoing historical practices which, literally and symbolically push undesirables aside into marginal or liminal spaces. Moreover, purification involves not only the decontamination of one's immediate surroundings, but the establishment of clear boundaries between social groups in order to bring order and meaning to society. Social confusion is avoided, therefore, by the "rejection of

inappropriate elements” (p. 35), in particular, those who appear ambiguous, whose status appears “indefinable” (p. 95), or who are of marginal significance (ibid).

Kristeva and Douglas’ theorizations, while based on traditional religious and anthropological observations, are relevant to the theme of abandonment as identified by survivors in this study. Survivors were absolutely cognizant of the fact that they were separate from their family, and that no effort on their part could bridge that separation. Moreover, for some survivors, the messages they received indicated that their family felt they would be better off without them. Anna stated:

I kept asking them—when am I going to go home for good?—*Oh, when you get normal*—that was the answer. And I never got ‘normal’. In fact, it made me retarded, more.

Further, while living in the institution, survivors were acutely aware of what Dorn (1999) calls “the politic-moral territorialisation” (p. 47) of disability, that is, their subjection to the physical boundaries which separated them from the outside world—“*I had disappeared from the planet*”. Thus theories of liminality, of being “jettisoned out of that boundary” are directly expressed through the experiences of institutional survivors who were powerless to alter the social and topographic boundaries which removed them from ordinary circles of family and social life.

The observations of Kristeva and Douglas are similarly propounded by other twentieth-century critical theorists who have rigorously informed philosophical discussion regarding processes of alienation in modern society. Critical theorists dating from the eighteenth century have long argued that the modernist march towards the “cult of progress” (Sim & Van Loon, 2004, p. 40)—whether through Hegelian theories of the dialectics of self-realization, or via Marxist tenets regarding the disjuncture between the ruling and working classes—fundamentally

includes experiences of alienation and distress. Marx in particular posits that the lack of belonging that alienation engenders is a direct and inevitable result of modern processes of labour and production. That is, within capitalist societies, workers are separated, or alienated from their position in and contribution to society. Further, critical theorists from the Frankfurt School offer rigorous critique of modernity and question the reasoning behind the “progress” that marked the catastrophic and human-engineered tragedies of the twentieth century. Adorno, Horkheimer, and Marcuse were among those working from positions of ostracization and alienation from the rapidly-advancing and discriminatory policies of Nazi Germany, and warned of the inevitable sense of relinquishment and estrangement that modernisation would precipitate to those considered marginal to the modern state (Simons, 2004a).

The critiques outlined above have informed disability scholarship addressing the abandonment of people with disabilities. While accounts of the exposure of infants with disabilities in Ancient Greece have been disputed in regards to their historical accuracy (Rose, 2003), the theme of being deserted by those charged with one’s care is one that remains relevant in disability scholarship. Ferguson (1994), in his volume *Abandoned to their Fate*, addresses political and cultural approaches to intellectual disability throughout the institutional era in the United States which subtly yet persistently perpetuated practices of familial and social abandonment, and propagated disabled individuals’ isolation and rejection from broader society. More recently, Corker and Shakespeare (2002), take a postmodern perspective in their position that assumptions of progress “at the heart of modernity” (p. 2) oppress and exclude people with disabilities and characterize them as logically “separate from and inferior to ‘normalcy’” (ibid). They contend that modernity’s “capitalist underpinnings” (ibid) have historically oppressed and marginalized people who fall on the unfavourable side of “axes of ability, gender, ‘race’, class,

sexuality, and age” (ibid). Further, Shildrick (2002) suggests that “standardising impulses of modernity” (p. 23) and the hegemony of positivist science have resulted in historical and ongoing processes of the rejection and removal of difference. Shildrick suggests that anxiety about difference tends to re-surface during “periods of social and political uncertainty” (p. 20); in light of the ubiquitous social and political concerns of the time period with which this study is concerned—that is, Cold War era apprehensions regarding the threat of the Other and the need for strong, conformist and patriotic family units—Shildrick’s insight regarding the consideration of social and political factors in the treatment of people with disabilities is an important one. Moreover, scholars have emphatically articulated the metaphorical and literal abandonment of people with disabilities in virtually all aspects of modern life—in particular, education (Hibbs & Pothier, 2006), work (Blanck & Schwartz, 2003; Malhotra, 2006; Wilton, 2006), and meaningful engagement within social, political, and citizenship circles (Beckett, 2006; Devlin & Pothier, 2006; Herr, 2003; Rioux, 2003; Thobani, 2007; Young, 1990). Last, Hubert (2000) speaks wrenchingly of the “desocialization and dehumanization” (p. 200) experienced by people with intellectual disabilities confined to a locked institutional ward, people who were literally abandoned by family and rejected by society (p. 197). These theoretical considerations, as well as the comments from survivors in the preceding discussion, suggest that it is indeed relevant to consider abandonment as both an abstract concept that speaks to alienation in modern society, and as an embodied reality felt by those who were left at institutional doors.

Ontological Meaning

Survivors’ experiences of abandonment also point to larger ontological questions concerned with the meaning and value of individual lives. In this study, the question that survivors repeatedly asked themselves, and indeed, demanded of the larger forces which led to

their eventual placement in an institution was—Why am *I* here? Why did *I* have to come and live here? Their questions, however, do not ask for answers that merely address the details of family situations and capabilities. Upon reflection, rather, their questions go beyond the pragmatics of circumstance and attempt to discern something far more fundamental: the ontological meaning of their lives which, it would seem, gives rise to the need for the questions in the first place. That is, survivors address something much larger than the myriad of outward reasons why they might have been sent to an institution—the skill level of their parents, the numbers of other siblings at home, the dearth of community resources and supports for people with disabilities, to name a few examples—and uncover a rather uncomfortable point of discussion which concerns the fundamental value of people’s lives, particularly when regarded as different.

Hughes (2007) has addressed these concerns in a heartfelt essay which discusses the vexations of attempting to reconcile the “existential mire” (p. 680) of a “postenlightenment humanism in which difference disappears into the abstract” (p. 677) and the reality that people with disabilities continue to “have to make a significant effort to establish their human worth” (p. 677). Hughes points out that despite repeated efforts by disability scholars to remind non-disabled individuals of the “universality of impairment” (p. 679) and the ubiquitous nature of human vulnerability, people with disabilities remain in the dubious position of having to repeatedly “make a claim to humanity” (p. 678), a position which more or less ensures that not all people can expect to enjoy full inclusion in the human family.

Statements made by institutional survivors in this project indicate that Hughes’ concerns regarding the “negative ontology of disability” (p. 678) remain valid in many people’s lives, and indeed continue to plague their emotional and psychological processing around why they were forced to spend so much of their lives in undesirable and sometimes abusive situations.

Survivors' deliberations indicate that all the reasons in the world do not adequately explain nor justify the treatment that people with intellectual disabilities suffered at the hands of a massive institutional organization, all good intentions notwithstanding. The fundamental point, regardless of the lack of family resources and societal awareness at the time, remains that people with intellectual disabilities were institutionalized because of their difference, a point brought up repeatedly by the questioning—*Why me?*—of those who suffered the most at administrative attempts to deal with the uncomfortable dissimilarities they presented. To that end, there is no satisfactory answer to the questions posed at the beginning of this section. When examined in light of Hughes' assessment, it becomes clear that it is people's fundamental and anxiety-provoking difference which led to responses which justified differentiation, exclusion, and incarceration.

Institutional experiences: Dehumanization and abuse

Finally, this chapter would not be complete without some mention of the more difficult experiences of people who survived institutionalization. While these experiences are not the primary focus of this research, they remain at the centre of the survivors' recollections of this period in their lives. Despite the acknowledgement that their experiences of self-worth, self-advocacy, and community involvement are far better now than they were when under the grip of institutional care, memories of institutional life remain painful pockets of memory that are easily recalled.

A principal reflection regarding survivors' direct experiences of institutional life was the prevailing culture of regimentation and lack of freedom. All survivors described the absolute dearth of opportunity to make their own choices, to determine their own schedule, or to wear, eat, or spend their leisure time as they wished. Absolutely every detail of their lives was

determined by the super-structure of the institution. All clothes were taken from them upon entry: food was portioned out to residents; days were ordered in exactly the same fashion, day after day after day. Walt noted “It wasn’t a different day; it was the same day. I guess every day was the same day”.

Concomitant with the overriding regimentation were feelings of powerlessness. Survivors learned that attempts to voice complaints, to argue for change, or to make even simple requests were usually fruitless, as they would not make any difference within the highly structured bureaucracy of the institution and its corresponding military-like culture. Indeed, several survivors reported encountering reprimands—*We’re the staff. You do what we say*—when requests for change were made, to the point of being punished for speaking out. Calvin spoke of being disciplined for requesting to turn the lights off when they went to bed, instead of waiting for the pre-determined “turn-off time”. This military-like ethos dominated institutions during the postwar era. As was explained by a former staff person and noted in a later chapter, regimentation would have been familiar to the large numbers of returning war veterans who were employed at provincial institutions during this period. While this does not necessarily mean that all veterans employed at provincial institutions approved of their militaristic style and methods, it does suggest that many had already experienced hierarchical and regimented methods to create order out of the inevitable chaos of huge numbers of people being housed together in less than favourable circumstances. These systems did not allow for fluctuations in schedule, and their goal was to maintain the running of the operation as opposed to meeting individual needs.

The rigidity with which the institutions functioned meant that facets of daily life within which dignity and respect for self and others are normally imbued were overruled by the seeming importance of schedule and discipline. This was particularly true in the years prior to the 1980s,

when normalization principles had not yet made their way into institutional care, and administrations continued to rely on long-established practices which did not take the dignity of residents into account. While some of the survivors in this study were still residents of institutions when these changes began to be made, all of them spoke of the lack of dignity with which most of the tasks of daily life were carried out. Irene recalled:

There was no privacy. When we'd go to the bathroom, there was no cubicles. It was all just one room with toilets.

For residents with more involved physical disabilities, 'slab' baths were used, a method in which residents were laid down flat on washing tables without curtains, and were hosed down in front of the other residents. Survivors spoke of beds being crammed close together and sleeping in a room with several other people. Calvin noted, "you didn't know whose bed was whose".

Survivors also spoke of the dehumanizing processes to which they were subjected. By dehumanization, I refer specifically to those processes that incessantly wore down survivors' understanding of themselves as meaningful individuals, and deeply challenged their sense of worth as human beings. While there was an aura of dehumanizing interactions throughout all layers of institutional life, survivors spoke most vividly about admission procedures, experiences of institutional labour, and the ubiquitously violent and disrespectful atmosphere of the institution.

Walt and Quentin, in painful recollections of their arrival at separate institutions, spoke of being forced to strip themselves of their clothing in front of admissions personnel and to surrender personal belongings. Walt painfully described:

It was scary for me just to get out of the car...and when I went in there, I went to the admission ward, and when you go into

the admission ward, they (*pauses*)... they strip your clothes
and you're naked and you're standing there, and they
measure you, you know, to see what are you wearing, your
clothes are all gone and they give you new clothes, their
clothes, like prison clothes.

Quentin, further spoke of a new, blue suit “that I had just bought. I had the blue suit on [when I went to the institution]... never saw that suit again”. The depersonalization these men experienced through the confiscation of what few items they possessed was their introduction to the extent to which the administrative body of the institution worked to suppress individuality and autonomy, potential threats to the disciplined running of the institution. Moreover, the forced nakedness to which these men were subjected is a blatant example of an abuse of authoritarian power; the threat of exploitation, put into motion as soon as the child is exposed, would ensure complete obedience.

All of the survivors referred to some aspect of institutional life that wore away at their sense of wellbeing. Many referred to the absence of anything personal: closets were communal, and residents were assigned two outfits which, it was made clear to them, were not really ‘theirs’, but belonged to the institution. Hilary, Anna, and Irene referred to ‘ticking’ dresses, a kind of uniform that was allocated upon entry that was uncomfortable and completely depersonalized. Hilary stated, “I only had two dresses, and they never let me wear my clothes—‘ticking’ dresses”. Hilary also referred to the institution-wide shaving of heads, a strategy employed to prevent the possible spread of lice: “They shaved my hair off—but my hair is grown in now”. Meals were communal and rushed, with no option for personal preferences. As Anna described:

The food was horrible... You only got to have ten minutes to eat, because thirty-one of us would line up and get our tray to sit down. Then we got served, and we took each individual tray to sit down, and by the time, if I was at the end of the line, which I was quite a bit, by the time I sat down, I didn't have time to finish. You got ten minutes to eat, five or ten minutes, to eat your meals.

Dehumanizing treatment was also indicated by survivors' descriptions of the labour they were forced to do while living in the institution. Notably, at least half of the participants reported doing the institution's laundry. Walt stated, "I had to clean the poop out of the linen". The labour exploitation of institutionalized people throughout the asylum's history has been well documented (Reaume, 2006, 2004, 2000; Simmons, 1982; Trent, 1994). Survivors' accounts in this particular study of having to do one of the most menial and filthy tasks of the institution—cleaning excrement out of residents' sheets and clothing—is indicative not only of the cost-saving measures that institutional administrations felt they could get away with, justified by the residents' otherwise "unemployability" (Reaume, 2004, p. 467) and that they should bear some of the responsibility of the upkeep of the institution, but also of the poor regard that institutional administrations bore for their residents. Indeed, who best to clean up the excrement of the life of the institution but those most representative of human waste? This is reminiscent of Kristeva's observation that in the modern critical theory tradition, Kantian ethics "have long governed modern codes... in order to give us control over our defilements" (p. 29).

Further, all of the survivors spoke of the pervasively violent atmosphere which penetrated the institution. Gord recalled:

It was rough. And the men's staffs used to talk dirty. Yeah, talk dirty, and I didn't like that, either. It was disgusting. And they used to do this (*indicates an obscene gesture*).

While this kind of communication was dehumanizing in its disrespect for the residents, it also carried the potential of spilling into violence. In all locations and routines, and in all avenues of communication, there existed an ever-present threat of physical violence should one not adhere to the conformity that institutional life demanded of its residents. "I got beaten up by some of the counsellors. Nobody stopped it...if you even looked at one of the counsellors the wrong way, you got beat up", Anna reported. "We weren't allowed to talk back...I got into trouble every day for something... Stupid little things, you know?" added Irene. In addition, survivors noted that staff facilitated an atmosphere of violence by inciting residents to act violently towards each other. Almost all of the survivors referred to the frequent bouts of aggression between residents. André recalled: "there's too much fighting going on...They fight in the morning, the afternoon, and night. That's too much!" Anna added: "It was just like being in jail. And you had the guards beat you up. And they instigated fights between us too, the staff". While distressing, the logic behind this thinking is clear: it is more difficult for a group of oppressed people to resist their oppressors if they are not united; inciting violence between residents was one way the administration could enact and justify disciplinary and controlling measures against them.

Sometimes, the violent atmosphere depicted above was manifested in instances of direct abuse committed against persons living in institutions. Again, while it is not the principal point of this research to delve into details of the mistreatment that residents of institutions suffered at the hands of their caregivers, several survivors were willing to share stories of some of their more difficult experiences. As four of the survivors explained, it is important for these stories to

be shared, first as a way through which to derive some meaning, and second, as a means towards ensuring that these atrocities are not repeated. In the words of Walt, who had seriously contemplated suicide after being released from the institution,

I am glad that I did not successfully end my life because [if I had] I would just be another victim of abuse who takes his story to the grave... I want to tell people what happened, so that the world will be a better place and so that I can make a difference in the world... I know that someday I will die, but I will rest well because I actually did something to help the community: speaking up to the world for what I believe.

While the principal thrust behind the abuses directed at residents of institutions seemed to be a combination of the overriding prioritization of order and demand for respect which the staff brought with them into their roles, it is clear from survivors' stories that their mistreatment must also be attributed to ill-informed and anxiety-ridden understandings of disability that imbued relationships between staff and residents. Survivors indicated that they have well grasped the fear and misunderstanding that many of the staff possessed while in their roles as caregivers, a fear that translated into aggressive and inhumane treatment. As Irene explained, the presence of people with disabilities challenged the staff's understanding of humanity, which, in their eyes, seemed to justify the poor treatment they gave to residents:

They probably didn't think we were human, or that we had any feelings of anything, or that we wouldn't know what was going on. Thought they could get away with it.

For some survivors, one of the more difficult aspects of the abuse came later in life, after discharge, when they learned through their involvement in the self-advocacy movement that the provincial government had been aware of the situation in institutions—indeed, had known about them for decades—and yet had done nothing on behalf of the residents in regards to their protection or care. For some, this was the ultimate desertion, as they had been entrusted to the province for their care, and yet the province had abandoned them. Walt explained:

They're [the government] accountable for each person who went in there....they thought this was a good place for all of us, and then they knew about it...they need to apologize to us....Shame on the government...the government was not innocent.

He suggests that the scarring with which he continues to contend is not only from the direct mistreatment that he suffered at the hands of people from within the institution, but from the neglect with which his legal caregivers and advocates ultimately treated him.

Frequently framed as punishments for misdemeanours residents had committed, mistreatment included various forms of disrespect and cruelty. These included verbal ridicule from staff; different meals for staff and residents; minimal time to eat meals, being sent to lie under benches for speaking out; staff instigating fights between residents; 'digging for worms', that is, lying on the floor with the hands tied behind the back and being forced to rub one's face on the floor; scrubbing the floor with one's own toothbrush; being sent, naked to isolation rooms; being forced to walk in front of the class with pants down; 'climbing the walls'; and last, accounts of horrific sexual abuse in one's bed or in the shower.

The abuse was contextualized as ‘deserved’, thus justifying its administration. This corresponds to what scholars of institutionalization have described as one of the effects of the super-structure of institutions: regimentation, punishment, and abuse are warranted in order to maintain its overall functioning. Essentially, the institution, as designed, could not operate save for strict adherence to schedule and use of punishment on residents. Moreover, the “defilement” (Goffman, 1961, p. 43) which residents suffered ensured that any hope they might have had regarding sustaining a sense of self within the body of the institutions was negated (ibid, p. 16), lessening their potentiality as threats to its operation. What is striking, moreover, is the specific cultural location of the abuse; it is highly unlikely that institutional staff would have committed the same kinds of atrocities on their own children, even for similar misdemeanours, once away from the institution. This raises questions about the implications of institutionalized care, not only in terms of residents, but also in regards to the moral and ethical reasoning of caregivers, a point that will be discussed in greater detail in a later chapter. Last, what the narratives above signify is that, essentially, residents were mistreated because they are people with intellectual disabilities, and are therefore somehow not party to humane systems of care and relationship. The very being of the person with the disability is brought into question through the blatant abuse directed at him or her: “Who am I as a person to have deserved this?”

Chapter Eight: Findings, Siblings

Introduction

This chapter addresses findings which emerged from the eleven interviews with siblings of people who were institutionalized. While not all of the sibling participants have direct connections with participants from other groups, there are some exceptions. Three of the siblings, William, Gregory, and Patricia, are the brothers and sister of two people included in the survivor group discussed in the previous chapter, Hilary and Gord respectively. Bertram, the father of Doris, another sibling, will also appear in the following chapter which discusses parent findings. Fiona, a sister of a man who spent time in an institution, discussed her reflections with me along with her mother, Elisabeth. And finally, two sisters, Michelle and Olivia, participated in this project along with both of their parents, Betty and Owen (the details of the interrelationships between various participants are given in Appendices C to G).

As outlined in the discussion on sampling in the methodology chapter, all of the siblings describe being raised in middle- to upper-class homes, or, as at least six of them pointed out, in homes in which the aspiration towards an upper class lifestyle was an underlying subtext to family life in general, and could be considered a factor in their parents' decision to place one of their siblings in an institution. Moreover, all of the siblings who participated in this study were well-educated (all having at least one post-secondary degree), articulate, and were willing to speak with me, factors that must be taken into account when considering the findings. That is, these were all people who were well able to reflect on their experiences, and, as it became evident throughout the course of the interviews, had already reflected on the phenomenon of institutionalization and how it had affected themselves and their families. While it cannot be known how the results might differ were a different group of siblings recruited, it is important to

acknowledge that this particular group of siblings represents only one segment of the population of families who would have made the decision to institutionalize, and that this specificity might be reflected in particular when considering families' reasons for institutionalizing a child.

The themes which emerged from this group can be addressed under three major headings. First, siblings' stories all indicated the existence of a particular family narrative which they felt needed to be upheld while they were growing up and which has continued on into their adult lives. These narratives included such phenomenon as the manner in which each family spoke of their institutionalized brother or sister, the particular family presentation that was given to the outside world, what was kept silent, and the toll that these narratives took on individuals and on the family as a whole. Second, siblings indicated that the removal of their brother or sister from the family home had significant consequences on them, including a ubiquitous sense of the need to make up for the absent child and the fear of also being sent away should they fail to meet those expectations. Further discussed in this section are the siblings' observations that difficulties within family dynamics were not resolved by the removal of the child with intellectual disabilities. Third, siblings noted their experiences of rupture, both personally and in what several of them called their 'family story'. For many siblings, this breakage continues in their lives, both in the gaps and absences in the lived story of their families, gaps which siblings have come to realize are unfillable, and through the paradoxical existence yet invisibility of the person with a disability. Again, siblings were clear that the ruptures that they have experienced continue to carry on in their lives as adults, and have resulted in a significant amount of psychological and emotional investment in order to come to terms with the more difficult pieces of their family histories. As Michelle stated, "this has been my life journey".

Before wading into these three major areas of analysis, however, it is necessary to depict the underlying tenor evident in most siblings' accounts. Eight of the eleven siblings expressed significant anger with respect to their parents' decision to institutionalize their brother or sister. While the most evident explanation for that anger includes the profound sense of regret and loss for a relationship that never had the opportunity to flourish, these siblings also acknowledged anger in regards to the far-reaching emotional and sometimes physical consequences of their siblings' institutionalization, many of which they did not come to recognize until adulthood. While in some cases, anger was directed at the 'system' for its inability to care adequately for their brother or sister, and siblings acknowledged that their parents had not had many options from which to choose in regards to their child with a disability, in general, siblings expressed disappointment in their parents for the choices they had made. Indeed, in at least seven cases, siblings suggested that the parents' decision to institutionalize a child was an example of their inadequacy as parents and their lack of commitment to a challenging situation. As Stephanie noted, "my parents were self-centred, very cowardly, [and] not good parents for many, many reasons". The pervasive anger expressed throughout the sibling interviews sheds light on some of the other themes that emerge from siblings' experiences.

Family narratives

All eleven of the siblings expressed, either directly or indirectly, the existence of a family narrative which was the principal story presented to the outside world in regards to their family constellation and how they appeared and functioned as a family. In most cases, there existed a significant disjuncture between the public family narrative, and what the family knew to be the real or accurate story of their lives together. Families did not necessarily live the public narrative differently than the one they lived within the private confines of their homes. That is,

the way in which families conducted themselves within their routines and traditions largely fit into what the public knew of them as a family. The important point here is the underlying knowledge of the other, real story of each particular family, a knowledge that, for the most part, was not available to anyone outside of the family, and in some particularly sad cases that will be discussed below, was not even available to all immediate family members, including other siblings. As Stephanie indicated, “I was always one of two children, before and after he was born, to the world”. Erin stated:

“I was in a family that actually had five people; Frank [her brother who did not know of the sibling with a disability] was in a family that had *four* people. It was a totally different family from his perspective”.

Siblings who experienced this disjuncture between the public presentation of their family and the more truthful narrative often found themselves in positions of having to defend their family in the presence of others. As Stephanie explained,

“I was afraid to mention it [brother’s absence]... I didn’t want them [parents] to be losers, so I tried to bolster them by just evading. I was afraid of destabilizing my family”.

As children dependent on their parents for everything, these siblings learned early on the necessity of acting their part in the public narrative of their family. In situations in which families were heavily invested in maintaining a particular public story, siblings learned the rules of the game early on: “I was instructed not to talk about him...I was a kid, a good kid, and I did what I was supposed to do”.

Beyond this public/ private divide, there existed further disjunctures within the privacy of the family home itself. In particular, there was a marked gap between the unspoken yet true story which the family was actually living out—that one person was missing and was living at a significant physical and emotional distance from the rest of the family—and the story within which the daily life of the family was embedded, a story which rarely acknowledged or discussed the person's existence, and accordingly, his or her absence. These families lived what might be called a double narrative: that of a normal family carrying on its day-do-day functions in a way which met normative socio-cultural standards, and the unspoken narrative, of which some parties were aware, that this presentation was incomplete, and essentially untruthful, even within the intimacy of family discussions and routines. While the existence of multiple narratives is not unique to families who have a disabled family member (Goodall, 2005; Vangelisti, 1994; Vangelisti & Caughlin, 1997), its mention is of import here, and specifically as a 'double' narrative, because of siblings' repeated reference to the marked distinction between two specific realities that they felt they experienced within the family home. When this double narrative was not shared by all members of the household—when, for example, one of the non-institutionalized children did not know that they had a sibling in an institution—the narrative burden on the knowing child was exacerbated even further. Erin explained, “I knew we were keeping this from Frank...I knew we were keeping it from him because I participated in that quite actively”. Moreover, siblings suggest that narratives often had several layers and differing manifestations which became more complicated the less the absent family member's existence was acknowledged, and that considerable energy was expended to prevent those narratives from colliding with each other both in public and private arenas.

Further, siblings indicate that the person's absence was not really an absence in the typical sense. They suggest, rather, that the missing sibling carried a significant presence in the home despite his or her invisibility, a phenomenon which Goodall (2005) likens to the power that unspoken family secrets can hold within family narratives, a power which only seems to increase the longer the secret, or, in this case, the absence of a family member, is held in abeyance. Indeed, many of the siblings noted the inherent irony of the situation: the physical absence of an individual from the home did not remove them from the family narrative; rather, their absent persona maintained a presence which often grew in figurative scope and size in spite of, and indeed because of that very absence from the home. Doris noted, "There was always this 'elephant-in-the-room' kind of thing... this thing that was never discussed, never acknowledged". Pauline likened the absence / presence of her sister to the presence in the home of the institution and all its residents, in its entirety. She stated:

When it's your family... it's as if the institution moves into your house. So, that person isn't there...So, you go from one little person who's moved, to a place of thirty-eight hundred people who somehow come home with you...it's an emotional place that travels.

Pauline described the implications of the sensed presence of thousands of institutional residents in her childhood home: "there was always a darkness, always a heaviness to that absence".

In most cases, the absence / presence served the particular function of casting a restrictive net over the type and range of discourse that was permitted in the family home. That is, discourse had to fit into the larger family narrative, and thus there were particular things permitted within this discourse, and simultaneously, there were unspoken rules regarding its

boundaries. As all of the siblings were young children when their brother or sister was removed from the home, the absence/ presence of their sibling and the particular discourse it engendered became the normalized comportment within which they learned to function, and from which they grew into adults. Most notably, all of the siblings except for one stated that their siblings' absence was something that they did not talk about at home. William, Gregory, and Patricia (the latter two of whom are brother and sister) stated that this was, in their estimation, not a burden. Gregory stated, "It wasn't that we couldn't talk about it [brother's absence]; it was that we *didn't* talk about it". Others described a more restrictive environment, and felt that the suppression of the real family story was an ongoing, permanent feature of their family life within which they were bound to participate. As Geraldine commented,

It was very shameful. And so Kevin was a secret. So, once he was institutionalized, he was never spoken of in a family context, *ever*. I knew of his existence... [but] we never talked about him.

For many siblings, the restrictions on discourse extended beyond the family home. Several participants recalled that many of their friends did not know that they had a brother or sister who lived in an institution. It became a secret that they did not share unless absolutely pressed to do so. As Doris explained, she told her friends that she had two brothers, when, in fact, she had three: "I was just tired of explaining". She was tired of explaining "this aberrant family to people" and chose instead to present an entirely different family to the world. Pauline described an identical experience: "I could never tell them [her friends] the story that I had a sister...They never knew... this was not a story to be shared". These women thus lived a significant part of

their formative years bearing an untruth, and feeling bound by that untruth in their friendships outside the family home.

Further, many siblings describe the precision with which they had to live their lives as children for fear of breaking the fragility of the untruthful narrative, and of upsetting the delicate balance between their public face, their parents' well-being, and the intimate knowledge of what their family actually consisted of. Stephanie stated, "You hold on to your image of your family against the world, right?" For many, family discourse involved a containment that took energy and care, a task which took a considerable toll on them. Even as children, they knew that speaking beyond the boundaries that the family had established was a frightening unknown that could be harmful, both for them and for their family. "I was careful", Erin stated. "[If I] provided this information when I shouldn't... this huge thing was going to unravel". Erin continued, explaining that on the occasions when the discourse was opened and a piece of the truthful narrative slipped out, her mother would cry, and "I always felt like she would never stop". For these participants, the unacknowledged narrative frequently took on a life of its own, becoming a raw presence, an entity which remains a source of pain in their adult lives. "When one of your family members goes there, that becomes a part of what you carry. And there's no way around it... I still carry all those years", Pauline explained. Indeed, for these participants, coming to terms with the balancing act within which they were required to participate remains a significant life task.

In the most extreme cases, the concurrent existence/ nonexistence of one member of the family, and the maintenance of an inaccurate narrative led to secrets within the immediate family itself. In one particularly heart-rending example, Erin described how her younger brother, Frank, the youngest member of her family, did not know that he had a brother with disabilities until he

was six years old. When he did learn that he had a brother, and that his family actually consisted of three, not two children, he was told that his brother had died. Thus, while Frank was admitted into a partial truth—that he did indeed have a brother—he remained unknowing of the full story, that his brother remained alive and was living far from home, in an institution. The rest of the family kept this piece of the story from him until well into adulthood. Such care was taken to maintain this particular version of the family story that Frank was not present at his brother’s funeral, a ceremony which took place *in the family’s own living room*. Rather astonishingly, the parents somehow managed to arrange a child’s funeral in their own home and yet simultaneously prevent another of their children from attending:

And so, when David died, Frank went to other people’s house overnight. He didn’t know. And [so, while] we had a funeral in the house, Frank was at a sleepover at somebody’s house.

As can be expected, when Frank finally learned the story in its truthful entirety as an adult, any trust that had existed in the family underwent significant breakage, and it remains “a hurtful topic between us... there’s a whole bunch of stuff about the fact that I didn’t tell him”.

While this is an extreme example of the kinds of secrets that can develop in families—to deny the existence of a child—other siblings spoke of their experiences of what might be called ambiguous secrets. That is, siblings described situations in which they knew of the existence of a child with a disability who lived in an institution, but had either never met the child, or had been so young when their brother or sister was removed from the family home that they had no recollection of him or her. Thus, while the existence of the missing child was not exactly denied, the child was spoken of so little, and in some cases, was visited so rarely, that some of these younger siblings barely knew of their institutionalized brother or sister. As

Geraldine explained, “how would he even know he existed? He had no memory, and there was no family talk”. In this particular case, Lewis, the brother of Kevin, who had lived in an institution from an early age “had not bothered to tell his wife that Kevin had existed... because he was that irrelevant to Lewis’s life, in Lewis’s opinion”. Stephanie spoke of the relentless sadness with which she has had to contend because of the fact that the only time she met her younger brother with Down syndrome was at his funeral. She vividly recollects her feelings of loss and confusion when her mother returned home from the hospital without the baby she had so looked forward to: “I wanted to know where he—if he’s not coming home, where is he? Who’s looking after him like I planned to?” She describes her efforts, even as a young child, to learn the whereabouts of her brother:

We were at some friends’ cottage in the area. We went to a restaurant in Orillia, and I went with this other family. And I remember leaving the table and going to a public phone booth and looking up the phone number of the place, just to know it was real. I wasn’t going to call, although I think I wished I could have. But I just wanted to know that there was such a place, and it just brought it closer to me, just seeing it in the phone book. So, you know, going off and not being able to talk to anybody about any of that.

Stephanie’s desire to learn more about her brother carried on into adulthood, to the point where she eventually took a job in the institution where her brother had lived, partly, she realizes now, in an attempt to fill the vacuum of knowledge that her family had left vacant around her missing sibling. As was true for many of the siblings, she describes her determination to find out as much

as she could about her brother; “it was absolutely, I had to do it”. Regardless of how much she later learned about her brother, the fact that she was denied the opportunity to see and touch him save for after his death, remains a devastating piece of her family story.

These siblings who knew nothing of their institutionalized brothers or sisters, or who knew of them but had almost no connection with them whatsoever, spoke clearly about their desire to learn more about him or her. As Erin stated, “I don’t know when it started, but I wanted pieces of information about David...it kind of intensified as time went on”. Thus, parental desire to keep their disabled child a secret, in an effort to either protect the family’s reputation or to protect their other children, had the unfortunate effect of both facilitating a longing for information about the missing child, and creating breakages within family relationships that would, in essence, never fully heal.

The maintenance of a particular family narrative, as discussed above, had several far-reaching implications and took a heavy toll on family relationships and individuals. In particular, siblings spoke of the maintenance of narrative which was hurtful to the institutionalized individuals themselves. In order to protect the parents’ decision to place their child in an institution, a discourse of derision around the child with a disability was sustained. Siblings describe how the child with intellectual disabilities was frequently referred to with a certain amount of disdain, and suggest that this was done to justify their placement outside of the family home. Michelle spoke of this in regards to her younger sister: “to us she was a mongoloid”. She went on, at various points in the interview, to describe the attitudes with which she was surrounded as she grew up concerning her sister who lived away from home in an institution:

So much of [my fear] had to do with the attitudes that I grew
up with about disability and about Downs...like, how ugly...

well, I guess the words were—she was retarded, right? There was something wrong with her genes, with her chromosomes...so she was never going to be able to do the things that we would do...she would be with her own kind...it was better for her. [Growing up], I think I had an attitude of superiority... I just saw her as this defective person.

Michelle spoke further about her realization as an adult of the effect that this ongoing narrative had had on her understanding of people with intellectual disabilities, an interpretation that meant she “could not see people with Downs as people”. Accordingly, she avoided people with Down syndrome for almost fifty years, and it was only in the last year that she was able to look at a photo of her sister and “see her strength and presence as a person”. Previously, she had looked at it and thought “Well, she just looks like someone who’s trying to have a school photograph, except she can’t really go to school”. Geraldine described how the discourse within her family home led her to understand her brother not as someone with a disability, but as someone who was “bad”. The narrative used in her family to explain her brother’s placement in an institution, and to justify her parents’ decision, included “framing him as a problem”, a problem which was solved by placing him in an institutional setting far from home, which the mother believed would provide the “highly ordered [setting] she felt he needed”. Pauline spoke of hearing her mother refer to her institutionalized sister as someone who “ruined our lives”. As a young child, she had difficulty making sense of this, and she formulated her own explanations. One explanation suggested that her sister’s ability to ‘ruin’ her family was directly related to her disability; another suggested that indeed, if her handicapped sister was able to ‘ruin’ her family, surely she herself could too—did this mean she also might be sent away to a facility far from home?

Thus, in many cases, the narratives surrounding family members who remained in the home were not ones which encouraged a deeper understanding of the child with an intellectual disability, nor did it facilitate healthy and formative relationships. Rather, they sustained a narrative of justification for their decision to place a child in an institution and defended an ideology which presupposed the need for people with disabilities to live in segregated settings away from their families. Beyond the public / private manifestations of this discourse, and the negative impact these often had on family members who were institutionalized, these narratives had other long-lasting implications on the family. What emerged in this study in particular were the effects of institutionalization on the emotional well-being of the siblings and mothers of the institutionalized child. The next sections will address these concerns.

Effects on siblings

More than half of the siblings described a particular phenomenon within their family which stemmed from the parents' belief that removing the 'problematic' child from the home would allow the remaining siblings to flourish more so than if the child with an intellectual disability remained. These siblings referred to parents' comments which suggested that they believed they would have more time, attention, and energy for their other children, energy which would be 'used up' by the disabled child if he or she were to remain at home. However, for many of the siblings, these intentions, likely grounded in reasonable parental understandings of the kind of attention that children need in order to be raised well, and supported by emphatic concerns from family doctors regarding the 'negative' impact of children with disabilities on their siblings, most often had a reverse and destructive effect. Siblings who spoke of this described feeling tremendous pressure to 'do well', both to make up for their parents' experience of loss around having a child with a disability, and to sustain the narrative of justification for

institutionalization that existed in the home. That is, were the remaining siblings to underperform academically and socially, even with the biggest distraction and drain on the family's resources removed, then parents' rationale regarding institutionalization for the sake of the siblings would be brought into question, and there would be cracks in the narrative of justification that parents had carefully constructed and continued to adhere to.

Siblings in this study felt this pressure acutely. They knew that their parents expected them to do well in all areas of their academic, social, and extra-curricular lives. Michelle stated "I had to be the smart one, and the successful one, and then, you know, it's like I compensated for Nora". In particular, parents expressed a keen desire for their remaining children to demonstrate a sound intellect, as if, somehow, the presence of intellectual brilliance in some members of the family would demonstrate that the child with the intellectual deficit was indeed an anomaly, a 'freak' of nature, had appeared in their family only by chance, and was not a reflection of the true capabilities of the family line. This happened most frequently in families in which intellectual and academic achievement was seen as an essential indicator of success.

Geraldine stated,

There was a lot of stuff around intellectual prestige... there was this thing around intellect that was a really big deal in my family... intellectual competence was really important.

Michelle noted,

So, there were the 'smart' kids—my sister Olivia and me—and there were the 'dumb' kids... the ones who were not working out so well. You know, the ones who you would not hold up and be really proud of, put it that way.

Erin put it even more bluntly,

In my family, unless you have intellect, unless you demonstrate intellectual capacity at a very high level, you don't have value... the brightest and the most intelligent among us are the ones who, you know, rise to the top of the value ladder in my house.

Moreover, siblings felt that underlying this general atmosphere of loaded expectations was the fear that if they were not able to fulfil their families' expectations, they could potentially meet the same fate as their brother or sister and be sent away. Erin continued,

You know, if you don't do super well, we'll ship you off—like, there's this sense of very, very high expectations of us. And the undercurrent of all those high expectations was—Well, you know, if you don't fit into this category, you're expendable, right? We had an expendable child.

This was re-iterated by several other siblings, most notably, women who came from families for whom class and socio-economic status was highly valued. Geraldine spoke of being sent away to distant family in Australia at the age of five for six months. Although this was likely due to the mother's exhaustion and the need to lessen the demands on her within the household, the young girl, within the context of one 'bad' sibling having already been sent away to an institution, saw this as a punishment for having somehow not lived up to her parents' expectations of her. In her words,

My take on being sent to Australia was because I was bad.

So, it was like—okay, you really got to watch out, or you get

sent away. They get rid of you if they don't like you—was
what I did with that.

Michelle recounted the story of her first day of kindergarten, when her mother left her at the school yard for the first time. Knowing that her sister had been taken to a 'school' and left there, not able to see her family for weeks at a time, terrified her. It seemed to her a very real possibility that the abandonment that her sister had experienced was happening to her as well.

It was not lost on the siblings that many people suffered because of the false dimensions of the ideal family narrative, especially the child who was removed in order to create the conditions seen as necessary for the other children to flourish. Particularly in homes in which the existence and institutionalization of a child with a disability was held in secret, either outside or within the home, siblings described significant negative repercussions from the micro-management of the public face of the family, and from the concurrent expectations of success placed on the other siblings. For example, Erin stated that her parents felt that they were creating a normal life for her and her brother by “disappearing” the brother with intellectual disabilities. As an adult, however, she came to learn how faulty that reasoning had been, that the disappearance of her brother had fashioned an unbearable family secret and had created fissures which have never mended. She notes that even now, she believes her parents would frame their decision as one that was good for their family: “if we feel anything, we should probably feel grateful that they did this”. Michelle stated,

I know she made that decision partly for us, which is a heavy,
heavy thing to carry—you know, she did it for us—thanks,
Mum...the thinking of the time was—the other children will
suffer.

Yet Michelle went on to describe the significant emotional and physical repercussions she suffered later in life (which will be discussed briefly below) because of her sister's removal, indicating that even if her sister had required a high level of care, the lives of the siblings left at home would have been simpler, less burdened by responsibility and guilt, and enriched by her presence. Indeed, most of the siblings spoke of the loss that all members of the family experienced because of a child's removal. Stephanie stated:

It's just this huge sense of loss and horror and sorrow and anger. It's just—we were wronged. I was wronged. My parents were wronged. And then, ultimately, he was wronged.

Erin stated: "There are so many things that are such a loss, like, what we would have learned by caring for him". Doris added: "The whole family was robbed of him, and he was robbed of us".

It is important to note, however, that the findings here are not completely unanimous. A few of the siblings, including those who experienced the hidden knowledge of their siblings' institutionalization as a burden, and who also suffered under the high expectations of their parents, articulated their siblings' removal as a relief. For some, the presence of their sibling was difficult and added to what was already a chaotic and reactive household. These siblings were aware of the stress that the presence of a child with a disability seemed to bring to the family, in particular the mother, and thus experienced their siblings' institutionalization as a reprieve, while simultaneously realizing that this removal did not necessarily resolve the unhealthy dynamics that already existed within the family home. For example, Geraldine noted that while her brother's absence was an "unaddressed absence" that "added to the terribleness" of an overwhelmingly poor family dynamic, she did not miss her brother when he was away—"it

didn't haunt me at all". It was simply "another layer" of a "huge stress" and an already complicated family dynamic, and her coping with the situation did not involve investing emotional energy into his absence, but rather included removing him from her life and getting on with it. Patricia was clear that not having her brother at home was a relief: "I would have found it very difficult to cope with living with him". She spoke of her great embarrassment around her brother as she grew older: "I did sort of shut him out of my life. He wasn't on my radar. I didn't want him on my radar". Pauline, while she was acutely aware of the terribleness of her sister living in an institution and the devastating effects this was having on her mother, notes that she did not really miss her sister at all during her growing up years: "I can't honestly say that I look at Elaine with any love". She refers to the relationships that other people have built with her sister over the years, and "I honestly can't get it. I can't feel it...it just doesn't happen for me". Thus, the sense that the family missed out on a significant relationship was not the experience for all participants; rather, even while knowing that institutionalization was not a good thing necessarily, some stated honestly that they did not miss their sibling, and the family situation would not have improved had institutionalization not happened.

Most importantly, however, all siblings recognized that it was not they who suffered the most in this arrangement. They noted that the child with the disability endured much due to the intentional re-framing of the family in order to save face or to create a particular narrative. They came to realize, often intuitively as children and in a more sophisticated way in adulthood, that the provision of a home that their parents so desired to give them, a home without the distractions and burdens of a child with a disability, was done at the expense of another person's freedom and dignity. All of the siblings expressed some concern about the kind of life their siblings would have lived in the institution, a life which, for the most part, was completely

unknown to them. Stephanie explained how her brother, because of her parents' decision to place him in an institution, was

never touched by love. He was never bathed by anyone who
loved him. [That] is just, it's just the biggest crime ever.

Erin described her ongoing deep anxiety about her brother and his life in the institution:

it's terrifying to me what his—like, that's the place I can't go,
is to think about what it was like for him there... I can't.

In a similar vein, many siblings spoke of their fear that their brother or sister had been abused, and yet felt completely helpless to assist in any way. Doris expressed tearfully,

to know that he had been so horribly harmed and nobody
could even say to him—*I know what happened to you*—as a
big sister, that's really hard.

It has been particularly difficult for almost all of the siblings to realize, some many years later, that their brother or sister likely suffered at the hands of the people to whom they were entrusted, especially in light of their parents' reasoning for their decision as something they did "for them". Patricia and Gregory, sister and brother to a man who lived in an institution for over two decades, stated that they were surprised and saddened to learn from their brother after its closure that the care he had received had indeed not been "the best of care". Thus, many siblings carried a significant burden because of their siblings' removal, experiencing an intensity of parental expectations, awareness of another's suffering, guilt, and helplessness to alter the outcome in any way—all experiences that their parents had ironically been attempting to avoid via the removal of the disabled child in the first place. Moreover, in the balancing acts carried out within families in order to reach what they thought was the best possible environment for their family,

ultimately, the life of the child with a disability was deemed less valuable. While parents might have hoped that they had done the best thing possible for all their children, sibling accounts suggest that indeed, the suffering that they encountered, and the even more frightening possibilities of suffering that their siblings might have experienced in the institutions in which they lived, meant that few of those aspirations were lived out.

Beyond their own experiences, siblings indicated another considerable consequence of institutionalization within the family. Unanimous among all sibling participants was the significant and long-lasting impact that the removal of a child had on the mother. Indeed, while this will also be discussed in the chapter which addresses the reflections from parents, it is important to include them here as well, as siblings, particularly women, were especially observant of the effect that the decision to institutionalize had on the well-being of their mothers.

Effects on mothers

Every sibling participant in this study indicated that institutionalization had a significant impact on their mothers. While some more serious than others, all noted that their mothers held some kind of regret or sadness for the rest of their lives, a load that was carried stoically and silently by some, and by others, was expressed almost constantly, a grief that, in the words of Erin, “came out everywhere, because it came out nowhere”. Thus the sadnesses that siblings in this study describe their mothers as experiencing can be discussed under two principal headings.

First, siblings describe mothers who bore the weight of having a child with an intellectual disability and their subsequent decision to place him or her in an institution with quiet acceptance. For these mothers, the disability of their children was an unfortunate life event that had simply happened, and needed to be dealt with. These were women who did what they felt was expected of them by their social position and by institutions in which a significant

amount of socio-cultural prestige was invested, such as educational and medical authorities. As Gregory stated, “My mother would be very determined to do the right thing, to do what she was, in effect, told to do. Quite strong on ‘ought’”. This man went on to add that “she would have made her decision based on what she felt was best for all us”, that is, all of the children and her husband; this participant is certain that she would not have included her own needs herself in her reckoning. William describes his mother thus:

Her faith meant a lot to her... And the practice of her faith
was paramount in her life. Part of her understanding of how
she lived out her faith was to accept the life that was hers to
live. Now, that meant accepting her children, that meant
accepting Hilary, and accepting some problems that we had
in our own family that she couldn’t do anything about.

For these women, accepting their child’s disability was a principal tenet of their lives, and this included carrying out what they believed was the best option for their child and for their family. This was not necessarily lived easily, however; Gregory, quoted above, stated that “one of the great regrets of my mother’s life was Gord... that was one of the greatest sadnesses of her life”. While it is not entirely clear whether her sadness revolved around the fact that Gord had a disability, or that she and her husband decided to institutionalize him, Gregory has indicated that she did carry these two truths around with her, bearing them as a part of her life that she perhaps would rather not have experienced.

While the men quoted above describe their mothers’ emotional status as a stoic fortitude to bear what had been given them, and to do what they ‘should’ within the confines of their social status, many other siblings describe a more demonstrative and emotional response by their

mothers, a response which had greater impact, sometimes debilitating, on the rest of the family. These siblings describe their mothers as experiencing intense grief which was expressed in various ways, more or less for the rest of their lives. Doris spoke of her mother's life-long depression after admitting her son to an institution:

I don't think my mother ever recovered from having to let him go. My mother then went into serious depression. Even suicidal... my mother never recovered.

Michelle and Olivia described how they felt that their mother suffered "years of self-recrimination" for her decision to place her daughter in an institution. While this mother (Betty, who is included in the next chapter) believed that her daughter needed extra support in order to live a good life, she felt that others could better provide this, and she could not imagine herself capable of that kind of commitment. Betty expressed a great deal of self-criticism, and, according to her non-disabled daughters, allowed her heart to "turn to stone" in order to cope with the breakage in her life and with her own sense of failure as a mother. Indeed, Michelle was deeply saddened by her mother's behaviour at her sister's death bed:

Well, I think for my mother it was a tremendous relief. And it was very strange, because when Nora died, you know, and most of us went in and were with her and touched her and said good-bye, and cried and everything—my mother didn't do anything. She just left the room. Didn't touch her, nothing.

Four other participants distinctly describe their mothers as 'criers', as being intensely and frequently emotional, usually within the context of trying to cope with having a child with an intellectual disability living in an institution. For all these women, there was an intense fear

while growing up that their mothers would not stop crying, and that the family would be left to cope on their own with an emptied-out and unengaged mother. Erin stated,

My mother was a huge crier...and the most difficult thing I experienced with her is, I always felt like she would never stop. She would grab onto me, she would hold me, she would hug me, and she wouldn't let me go.

Stephanie described her mother's ongoing fragility which surfaced any time discussion around her son in the institution arose. In particular, she remembers the family attempting to make funeral arrangements after her brother's death,

and my mother refused [to go to the funeral home]. And it was that scene again of her emotion and everything... she should have been there with me. We should have done it together.

Pauline described her mother's gradual slide into a dark space around her daughter: "Mum had no capacity to cope, really... she became an insomniac, very, very teary, just more and more incapacitated", and the struggle her mother went through each week on the drive home from the institution where they had visited her sister: "on the way home, it was always—poor Mum. And she would sit in the front seat, sort of with her head down". Pauline went on to contextualize the sadness exhibited by her mother on their drives home within the larger milieu of a mother's unending sorrow:

There was no way that Mum could feel better—whether Elaine was at home, or whether she was in the institution, or whether she was driving, or whether I was driving—she

never got herself out of the funk of her feelings about having had Elaine. She just never, she could never—turn the story, I guess—she would just never do it... Mum’s ploy was always to sort of put her head down and cry, whether she was sitting in the car or sitting on the couch, or lying in bed, it didn’t matter, that was her signal to all of us—I’m not going there.

One of the women from this group, Stephanie, provided an interesting insight here. She stated that while it was perhaps important for mothers to cry, it seemed to her that mothers were crying more for themselves than they were for their children.

They’ve cried and cried and cried over the years. But maybe a little bit more for themselves—because they lost a child, or they had to deal with this, and other people didn’t—the sort of ‘why me?’ questions that anybody asks. They’ve cried and cried and cried...but maybe the mothers should start to cry for their children, and that’s what they should have done.

Stephanie’s observation, based on her experiences with her own mother, was that these women remained devastated over the birth of a child with a disability but that they were not able, in the words of Pauline, above, to “turn the story around” and use that sense of loss to work for something better for their children. Thus, their “great sadnesses” might have been more about their own loss, never fully resolved, than about the suffering of their children.

Further, the four siblings mentioned above, all of whom were girls, described being thrust into the role of family leader and replacement mother at a very young age as their mothers slid into increasing depression and incapacity. These women spoke in particular of the role reversal between themselves and their mothers. Doris explained:

One of my memories is my mother sitting on the couch feeding Michael... [baby brother, prior to being institutionalized] and directing me to open a can of soup and put it on the stove. And I'm five years old. And then, her being so angry with me because it went dry... I remember thinking—*I'm just a kid. I don't know how to do this.*

Stephanie described her mother's return from the hospital without her baby brother, when she was four years old, as the moment when their roles were reversed:

I see that as a turning point in my life, where my job was to look after my mother after that, not her job to look after me. Because she was this vulnerable person, I was supposed to be strong.

Pauline spoke at length about her role as family facilitator in light of her mother's incapacity:

I was the decision-maker in the house, probably from the time I was twelve or thirteen. I just did it. It didn't occur to me there was any choice. So, that became my role... part of my job was to keep my parents happy... it was my role in the family to facilitate everybody else...getting them up and getting them moving...sort of trying to keep

everybody else's spirits up a little bit...as for my mum, it
[having a child with a disability] just drowned her, and my
role was to keep her swimming.

Last, Erin spoke of her need to be 'perfect' in the face of her mother's grief, grief that "came out everywhere, because it came out nowhere". As a young girl, she recognized that the knowledge her parents held around her brother in an institution, a secret that they kept even from another child, forced her mother to keep her memories and emotions in check, which in this woman's memory, meant an ironic seeping out of sadness all the time, in front of which she learned to be utterly perfect. "I was perfect. I was three. How perfect can you be at three? That's not natural, right?"

All of these stories illuminate a harsh irony in the lives of families with an institutionalized child. While the parents had attempted to create a family that was indeed perfect in appearance from the outside, and a home that allowed children room to grow and flourish without the extra burden of a disabled child, the emotional toll that removal of the child took on the mothers resulted in unusual home situations in which children, girls in particular, felt the need to sustain and encourage the entire household at a very young age. The perfect home that their parents had hoped to create became impossible within the rubric of secrecy, expectations, and debilitating sadness.

Moreover, the findings above hearken back to discussions in Chapter Five regarding the role and social position of women during this particular era. As was the norm throughout this period, all of the mothers of the participants quoted above did not work outside of the home; their primary roles were homemaker and mother (of the remaining mothers of the siblings in the study, two worked outside of the home; the remainder stayed at home). Thus, the extreme

emotion that some of these mothers demonstrated could be interpreted as a complicated mixture of grief over having given birth to a disabled child, a circumstance unworthy of the social status that most of these women recall their parents striving continuously toward, and a sadness about their own capabilities as mothers, that sending a child to an institution was indeed an indicator of their incapacity. Doris explained that for her mother, watching her son disappear down the long, long hallway of the institution with a complete stranger was debilitating both because she was giving his care up to the state, and because it affirmed her own inability to care for him.

Last, siblings' observations indicate that the marriages of several of the mothers who struggled significantly with the birth and eventual placement of a child with a disability were also fragile. Siblings suggested that while the difficulties within these marriages could be attributed in part to the presence of a child with a disability and his or her placement in an institution, these concerns were also another layer of tension in an already-unstable situation. Geraldine stated,

It was a really, really bad scene. Yeah, the household was a mess. It was an absolute mess... there were so many things going on in the family, but to say that *this* was the definitive piece that was one of so many definitive pieces—the relationship between my parents was terrible anyway. I think it added to the terribleness of it.

Erin described what she perceived to be a 'deal' between her parents, an arranged agreement in regards to the maintenance of a relationship with their institutionalized son. She believes that her parents' decision to institutionalize him, and how visits were conducted, were conditions of the survival of the marriage:

I don't know who made the decision to institutionalize him. But I tend to chalk it up to my father. And I tend to feel like my father decided that she couldn't visit him, because she would get too upset...I think it was my Dad who said—I'll go visit every week. Whether he did or not, I don't know... that *he* would go to get my mother *not* to, to disengage completely and for her not to have anything, and I think that was the deal. Like, I think the deal was that she basically had to disengage and that was the basis of their continued marriage... my dad, he couldn't have handled, like, every week if she visited, her coming apart.

Stephanie referred to a similar process. The fragility of her parents' marriage was protected by removing the mother from decision-making and communication concerning the institutionalized child. Excluding her from these difficult areas might have been one way to maintain their relationship and to ensure some semblance of normalcy in the household:

My mother had always kind of been kept out of it, apparently. That the men had taken over—the doctor, her father, my father—was the way I envisioned it. [They took over] everything...she was needy, and couldn't deal with this, so the men had to do it.

Thus, for some of these siblings' mothers, the fragility they felt around their institutionalized children was complicated by further emotional arrangements that might have been necessary in order to maintain other relationships, namely, their marriages.

Rupture

The final principal theme which emerged from the interviews with siblings is that of rupture. While this was not a theme which emerged in every interview, it was of such significance in some of them that it requires some discussion, if anything to indicate the depth of the impact of institutionalization in many people's lives. While most of the siblings noted that difficult family dynamics existed prior to, and emerged from the decision to institutionalize a child, some described significant personal and family rupture with physical, social, and emotional manifestations.

The examples of rupture on which I would like to focus take different forms. First, some of the siblings described experiencing their brother's or sister's removal as a breakage in the family story, and that there remain chapters in their lives that are unknown to each other. While this was true of all the siblings in this study, for some this was more troubling. Doris, whose brother did not communicate verbally, juxtaposed what she knew of her brother who lived in an institution, and what she knew of her two other brothers:

With my other brothers, I don't know their entire life stories,
but I know big chunks of their life stories, and I know lots of
things about them that my parents don't know. And I don't
have that with Michael. I don't have that shared
history...there's a whole bunch of stuff that I just don't know.

This was particularly difficult for her when she suspected that Michael was being sexually abused, for there was no way to determine from him what was really going on in his world. His vulnerability and her powerlessness in the situation were extremely frustrating for her. Similarly, Patricia described her shock when her brother Gord, who had lived in an institution for several

years but at the time was living in the community, described the violent atmosphere of the institution, as well as some of the rough treatment he encountered. It was a piece of Gord's history of which Patricia had been completely unaware; she, as well as the rest of the family, had believed he was receiving "the best of care", and was saddened to learn only decades later that he had likely been mistreated at some point during his time there. These examples of the gaps between siblings' understandings of their brother or sister's lives in the institution and the difficulties with which most of them lived are indicative of the vulnerability of people who lived there. Because of the lack of family contact, and because of some residents' lack of verbal communication, families were never truly informed, from the perspective of the institutionalized individual, of the extent of their actual experience.

Second, rupture was experienced by some siblings within the context of the death of the child who was institutionalized. For these siblings, their brothers' or sister's death and subsequent funeral and burial were examples of breakages which already existed in the family, and of the injustices their siblings had suffered throughout their entire lives. Stephanie explained that the only time she ever saw her brother was at his funeral. She is deeply saddened by that knowledge: she never touched him, never spoke to him, never played with him, ever. And in a process from which she continues to learn, she confessed that it took her many years to tell her own children about this brother, their uncle who had existed but was absent from the family story. Yet while Stephanie experienced a profound sense of loss over the brother that she never knew, and that the funeral was "the realest it got... there was a role to that, as strange and as horrible as it was", somehow seeing her brother just once influenced her decision to become a social worker and to work with families in similar situations. Erin spoke of her ongoing struggle to learn where her institutionalized brother is buried. While the family did have a funeral, albeit

secretly, with another sibling absent, she has no knowledge of where her brother's body was finally laid to rest. Erin explained that this has meant a continuous grieving for him, and that it perpetuates the 'absence' that his life symbolized. In death, as in life, he remains absent and unknown; with no physical place to which she can direct her attention, she feels his story remains unfinished and untold:

I would just say my own personal experience of grieving him which I have done my whole life, without any of the information, like in a vacuum of information, because I can't access it, although I've tried....it's all about the things that I should have done or could have done.... it mostly has to do with a feeling like if the only thing that I have left to be able to do, is some kind of assurance that he is properly buried and remembered, then that's what I can do...I can't do anything. I don't, I have nothing left to do.

She goes on to say:

He's unremembered in lots of ways... he's like the hidden kid. So, how do I unhide him? How do I bring him into the light... How do we deal with all these invisible people?... He wasn't even permitted to be known by people in such a way that he could live on.

Powerfully, this woman suggests that the indifference with which people with intellectual disabilities have been treated, even in death, disallows them participation in the larger story of the human family. Her brother's life was not acknowledged in a way that allows him to "live on"

in anyone's story, except in terms of loss and breakage. For her, rupture was experienced through the gap between what little she knows of her brother's life and death, and what really happened to him, a gap which is unlikely to ever be reconciled.

Michelle spoke of the distress she experienced over familial disagreement over her sister's final resting place. Her parents determined that it would be best to scatter their daughter's ashes. Michelle, however, felt that her sister needed a "place", that for her whole life she had been denied the opportunity to have a place of her own and that now she could lay claim to one small piece of the world. Her parents refused, and to the sibling, it was devastating. "To me it was a re-enactment of the very thing that had happened in the first place, when they took her away". The fracture in understanding between herself and her parents is something that will never be reconciled: "there are some things I really can't share with my parents. They will never get it, and you know, I can never share that part of myself with them. That was so hard".

Other siblings spoke of the rupture that has happened in other family relationships as a result of the maintenance of false family narratives and the upkeep of secrets regarding the child with a disability. Geraldine referred to a younger brother, who would not have remembered his brother before he was sent to the institution, and who is now estranged from the rest of the family. As she noted sarcastically: "You think there's a reason why maybe he's estranged from the family? Yeah, yeah, it was a mess". Erin and Pauline also noted the estrangement of their brothers from the rest of the family—brothers who were either not aware that a child with a disability existed, or were somehow excluded or excused from taking any responsibility with their sibling's care in later years. Both these women described their relationships with their only remaining brothers as difficult and virtually non-existent when it comes to shared history and decision-making.

Finally, Michelle described her experience of the physical manifestation of rupture with her institutionalized sister Nora. She does not specifically remember their time at home together before her sister was institutionalized at a young age. She does know, however, that Nora was taken from her without explanation, and that her playmate had been replaced by a ‘discourse of justification’ regarding her and her need to live away from home. As an adult, she began to experience this loss in an embodied way, experiencing pain in one part of her body, eventually coming to learn that the pain was a manifestation of the burden of sadness and guilt that she felt around Nora’s departure. Not until after Nora had died, and Michelle had taken steps to ritualize her leave-taking from her, did the pain in one part of her body cease to haunt her. In Michelle’s words “this is the first time in my life that I’m by myself”. While this is an extreme example of grief’s manifestation, it is illustrative of the potential depth of the wounds caused by a child’s unexplained and sudden removal from the family home.

Experiences of institutions

As with the survivor group, although the direct experience of institutional life is not the main focus of this study, I feel it is important to include some siblings’ memories of the institutional life that they encountered during family visits. Not all of the siblings entered the institution directly. Of the eleven participants, Stephanie, Erin, and Geraldine stated that they never visited the institution. Patricia and Gregory stated that although their family visited, they never went right inside the institution; the family conducted its visit in a designated visiting area or took their institutionalized family member out on some sort of outing. The remaining six siblings vividly described their encounters with institutional life and its residents as young children. All of these siblings spoke of these visits as frightening and overwhelming. Pauline explained:

I remember how incredibly rough she was. Those kids were like something out of Dickens...it was really a rough and ready place....I'm sure there were lots of spankings and lots of rough behaviour because Elaine was incredibly rough.

Fiona spoke of her fear of entering the institution.

I remember walking down the hall at [the institution] and just being scared... all the people around. I remember the swarm, like, people just congregating, coming, convening around...people were desperate for interaction.

Michelle stated:

I was extremely traumatized by going into that place...as a small child, like, a four-year-old or five-year-old, walking down those long halls and you'd be passing all these people who looked strange and were kind of funny-looking and were saying things to me I couldn't understand because of their speech impediments, and... they were really wanting to be friendly, so they would kind of come up to you and go—*Waah*—and kind of grab, and to me, it was absolutely terrifying.

Her sister Olivia reported a similar experience:

I know I used to be scared going to [the institution]. Everyone would come up and touch you. I remember being very scared about that.... some were far more disabled than

Nora, you know, so there were some who were quite non-verbal and acting out. I remember seeing someone tied with a skipping rope into a chair, and things like that.

These siblings who had direct encounters with life in the institution confirm the scholarship of earlier chapters which address the extent of the dehumanizing and debilitating effects of institutionalization on people bounded by its limits and disciplinary practice. Goffman's (1961) analysis, for example, suggests that the "total institution" (pp. 1-24) functions akin to industrial management (p. 75), in which human objects are moved through the system in order to keep the institution functioning smoothly, even at the expense of basic standards of humane treatment. Within this scenario, wherein residents have been "deserted by society and turned out of relationships by those closest to [them]" (p. 141) and carry extreme positions of subordination, the seeking out of affection and attention from visitors who have suddenly re-entered the institution is understandable. Despite the desire of institutional officials to keep residents in order through "regimentation and tyrannization" (p. 38) and the constant penetration of all interactions (ibid) through surveillance (p. 7), residents are propelled instead "further and further into psychological and social states that are perceived negatively by others" (Hubert, 2000, p. 5), and thus, in the words of one participant, become "desperate for people". Accordingly, siblings who visited their brother or sister in the institution while young, often extending through their teenage years, did not see this as a positive encounter. For them, it was not an experience of re-connecting with a sibling with whom they had minimal contact; rather, it served as a limited and negative template for what it meant to have a disability, and what might happen to you if you were so labelled. As Pauline summarized, "We would go every Saturday. Every single Saturday. And that continued. I got married when I was twenty, I think to get the hell out of there".

An undeserved life

I conclude this chapter with a comment made by Fiona, one of the sibling participants in this study, who, although claiming a less traumatic experience than some of the other siblings—her brother Steven was institutionalized for a shorter length of time than most, and she has had a close and open dialogue with her mother Elisabeth about his institutionalization—made a striking remark about the effects of institutionalization on her own life. Fiona has worked tirelessly as an advocate on behalf of her brother and others with intellectual disabilities; indeed, she sees this as a calling and has done significant work in ensuring better lives for people now living in the community. However, when she reflects on what she imagines for her life in the future and what she might wish to aspire towards, she states that she doesn't “really deserve to have a good life for myself”. In light of what her brother has suffered, Fiona will not allow herself to imagine a life that is full and content; she does not believe she is worthy of it. While this is a particular example of the way in which one person has absorbed the negative repercussions of institutionalization on their family, and is not necessarily the way other siblings have coped with their experiences of ‘survivor guilt’, it is nonetheless indicative of the potential for ‘seepage’ of one family members’ negative experience into the lives of those closest to them.

This chapter has presented findings from sibling participants in this study. The overall timbre of sadness and loss is notable. In the final analysis, these observations will be juxtaposed and analysed in conjunction with the reflections from all of the other findings chapters. In the next chapter, we turn to the findings from interviews with parents.

Chapter Nine: Findings, parents

Introduction

Eight parents, two fathers and six mothers, were interviewed for this study. Four of these participants (Bertram, Elisabeth, Betty and Owen), are parents to four of the participants in the sibling group (to Doris, Fiona, Michelle, and Olivia). None of the parents are mothers or fathers to members of the survivor group; indeed, the children of Bertram, Kip, Louise, Betty, and Owen have already passed away (the details concerning participants in the parent group are found in Appendix E). As discussed in the previous chapter and in the methodology chapter, all of the parents in this study identified as belonging to either the middle or upper class, although comments from Bertram and Elisabeth suggest that they had worked steadily from more humble origins to achieve a particular level of comfort for their families.

Further, and as previously discussed, a gender imbalance exists in the parent group, which should be taken into account when considering the findings from the research. The reasons for this are based, in part, on life events: most of the fathers who might have been eligible to participate in this study have already passed away, and thus the recounting of family details has been left, for the most part, to their surviving spouses and children. While it is difficult to know the full implications of this gender imbalance in the parent findings, the heavier representation from mothers as opposed to fathers does give a full picture of mothers' roles as the person within the home who carried the majority of domestic responsibility, and indeed, that they carried the bulk of that responsibility alone. The inclusion of two fathers does, however, provide a window into the kind of influence fathers carried within the home, as well as their significant responsibilities in work and community endeavours outside of the domestic sphere. As we shall see, these kinds of arrangements have played a role in some of the decision-making

that families felt compelled to undertake concerning their child with a disability. Apart from Elisabeth, who was sixty-nine years old at the time of the interview, all of the other parent participants were in their 80s or 90s, ranging from eighty-three years to ninety-four years at the time of the interview.

While the original intention had been to include only parents who had institutionalized a child, at the conclusion of this phase of the research, I decided to include two mothers, Kip and Claire, who had kept their child at home, as their input was relevant to the principal theme regarding the impact of institutionalization on family relationships and understandings of disability. As parents who were also raising children during the time period addressed by this study, their input sheds light on relevant political, social, and cultural conditions, and expands our understanding of the context within which parents were making decisions which had significant bearing on their children.

The most evident finding emerging from parent interviews is the divergence in opinions and interpretations in regards to the experience of having a child with a disability, and in parents' understandings of the role and significance of institutional care. There were wide variations in parents' comments regarding their understandings of disability, in their perceptions of the possible responses and courses of action available to them, and in their interpretations of the impact that their eventual decision had on the rest of the family. While some themes do emerge from the group as a whole, the variance in experience as articulated within each of these themes is striking and will be addressed below.

Three major themes emerge from the parent interviews. First, parents identified that the lack of community support for families with a child with a disability, in conjunction with the bureaucratic underpinnings of post WWII life in Canada contributed to many parents' decision to

place their child in an institution. Political and social conditions, including class constructs, the education system, and bureaucratic arrangements that one needed to navigate in order to participate meaningfully in society were significant factors in familial decision-making. Second, parents addressed specific home and family concerns in regards to having a child with a disability and the impact this had on family relationships, understandings of disability, and how they regarded institutionalization as an agent of care. Third, parents articulated a theme which has emerged at various points throughout this research, one which suggests that the role of women and the social and political constructs of women at the time were key factors in decisions to institutionalize a child with a disability. The chapter concludes with a brief reflection on parents' views of disability, as the findings here suggest that these play a role in the decision to institutionalize.

Bureaucratic constructions

All of the parents interviewed for this project identified government policy and the absence of community resources as having significant bearing on the placement of their children in institutions. Simmons' (1982) assessment regarding the development of services for people with intellectual disabilities in Ontario, that is, that policy did not emerge from "clearly defined positive policy objectives, but rather out of a set of quite negative considerations" (p. 27), suggests that historically, there was little government impetus towards the establishment of supports for people with disabilities and their families throughout the first two-thirds of the twentieth century, other than the expansion of existing custodial institutions (Radford & Park, 2003, 1993b; Strong-Boag, 2007). Gradual increases in the numbers and visibility of people with intellectual disabilities in the community and within family homes did not correspond to an increase in government funding for services, nor to policy that would ensure people's inclusion

in non-segregated education, work, and regular civic life until well into the 1970s (Buell & Brown, 2003). Accordingly, parents with a child with a disability were left with two principal alternatives: one, to keep their child at home and assume full responsibility for their care, including his or her education, or surrender the role of ‘parent’ and allow the child’s care to be subsumed by the state via admission to a government-run institution (Simmons, 1982). The political and social services climate at the time made it difficult for parents to imagine or to enact alternatives that fell somewhere in between these two possibilities, and many parents who struggled to care for their child on their own ultimately chose the only other option available to them. As Claire, a mother who did not institutionalize her son stated, “I don’t think parents had a choice—if nothing or an institution—that’s not a choice”.

As Gleason (1997), May (2008), and Helleiner (2001) have indicated, the social, moral, and political climate during this era was not conducive to families, particularly mothers, creating alternatives for children who fell outside socially-defined boundaries of normalcy. Many families, in accordance with the “the politics of containment” (Cavell 2004, p. 13) and the “culture of regulation” (ibid) which dictated public policy and expectations regarding the behaviour of the populace during this time period, felt compelled to adhere to the options available to them. The lack of possibilities for people with intellectual disabilities in the community, in combination with a political climate not conducive to the development of further resources, led many parents to institutionalize their children. Almost unanimously, parents stated that their decision to institutionalize had been at least partly based on the lack of resources, lack of support, and few choices available to them. Bertram stated:

Well, it was a lot of work for my wife...there wasn’t
anything here... there wasn’t support for anybody... and she

said “I can’t keep doing this all the time”...it ended up that
he was accepted down at [institution].

Elisabeth, who spoke openly of her regret regarding sending her son to an institution, said,

They left some spaces for kids to be admitted directly from
home. So, that’s how Steven got into the institution system.

There wasn’t a choice; there was nothing.

Gregory, a sibling participant who offered insight in this area, stated, “I don’t think she ever
regretted sending him away; I think she regretted that there weren’t other choices”.

Some parents, however, felt that their children did not necessarily suffer as a result of
the narrowness of choices in regards to services for children with disabilities. Three mothers,
Susan, Betty, and Louise, were accepting of the custodial model; this was what was being
presented by the government, and they were content with the offer. These mothers did not
question the care their children received, and indeed were very positive about what they
perceived to be the best possible option for their children. Susan noted,

We made the decision to enrol her there, and never looked
back...my daughter blossomed at [institution]...we felt very
confident we were doing the right thing.

While the details of these particular parents’ views on institutionalization will be explored in
further depth below, it is important to note that while there were limited options for parents
overwhelmed with the care of their child with a disability, parents experienced these limits very
differently. For some, it meant having to choose between two difficult and seemingly
irreconcilable options: keep the child at home and struggle to provide adequate care with little
respite, or choose an institutionalized setting that inevitably created a certain amount of breakage

in family relationships, regardless of how faithfully the family visited. For other parents, such as the three mentioned above, the option to place their child in an institution did not contradict what they believed was best for their child, and while their decision might have been different had community resources been available, they did not regret their decision, nor did they seem to feel the need to imagine that there might be something possible besides the two limited options previously mentioned.

Some parents recalled further elements of the bureaucratic system which made it difficult for them to choose alternatives other than institutionalization for their children. In particular, two parents, Elisabeth and Bertram, referred to a frustrating situation which developed after school boards subsumed the administration of segregated schools initiated by parents' associations. While in essence this was seen as a positive step towards inclusion, it also contained a bureaucratic caveat with significant implications, as described by Elisabeth:

By that time, the school boards had taken over the segregated schools that the associations had started. However, they also inherited the admission criteria [which stated] you had to be toilet trained. I fought that... and all I got was—*You want teachers to change kids in schools?*—Anyway, so they wouldn't let Steven go to school...that's what the rules were. And the doctors wouldn't sign and the School Board wouldn't change...so, okay, I can't, I don't know how to do this. I didn't know how to do it... And so I said okay. So, Thomas [husband] and I walked Steven up the five-eighths of a mile corridor at [the institution].

Elisabeth reluctantly admitted her son to an institution, viewing it as a temporary situation in order that he might gain the self-care skills deemed necessary to meet the admission criteria to go to school. Despite the promise of a more integrated and publicly-funded education for Steven, she felt resigned to admit him on the precepts of benefitting from a rigorous training programme conducted by professionals in the institution so that this might happen. Elisabeth was acutely aware of the implications of even this one requirement on several hundred people: “you know, the numbers of kids that were sentenced to go to places because they weren’t toilet trained...” Also notable here is the unfortunate but popular conviction of the need to make use of a professional training programme (in this case, a toilet training programme being evaluated through a university study connected to the institution) to help a child establish a skill that the family might have been capable of doing on their own. This persuasion by experts of the need for professional expertise, what Trent (1994) describes as a manipulation of the “contours of both care and control to ensure personal privilege and professional legitimacy” (p. 5), reinforced widespread belief in the supremacy of institutional care over that which parents could provide.

In bumping up against the bureaucratic restrictions that existed at the time, parents were subject to what Bourdieu (1990) calls the “constraints and limits of the habitus... [the] product of history which produces individual and collective practices” (p. 54). The praxis of institutionalization, deeply engrained in Ontario’s response to intellectual disability, is, in this view, an example of the habitus’ historical product, carried out in “accordance with the schemes generated by history” (ibid). The habitus “guarantees the ‘correctness’ of practices and their constancy over time....and generates all the ‘reasonable, common-sense’ behaviours (and only these) which are possible within the limits of regularities” (p. 55). In this analysis, parents who ultimately decided to institutionalize their children can be understood as acting within the

confines of a deeply-engrained “product of history” constituted by collective practices, a product which ultimately determines what choices are possible, “of what is appropriated in advance by and for others and what one can reasonably expect for oneself” (p. 64). Our willingness to engage with the habitus is, according to Bourdieu, what “enables the institution to attain full realization” (p. 57) and to achieve sustainability.

In light of Bourdieu’s analysis, it is also important to consider those parents who, despite facing similar socio-political and economic circumstances and identical bureaucratic limitations, chose not to engage with the “product of history” in pre-determined ways, but rather positioned themselves outside bureaucratic boundaries and kept their children at home. While the bureaucratic labyrinth often made institutionalization the easier option, many parents chose instead to work for years, often in isolation, to establish meaningful and alternate support systems for their children. This was not an easy undertaking. The social and political milieu of the time made it difficult for families to connect with each other and to act as resources for each other. As Claire stated,

I didn’t meet any parents. It was very hard to find out who’d had a baby—it’s private information. You can’t get it from the hospitals, you can’t get it from the nurses, there’s no way to get it; you have to wait to find out about it... we never got it formalized because you’ve no way of accessing the information.

With no information available to parents and newly-established associations, parents were entirely on their own. As Kip explained, “I speak from a different era, where there was nothing for them at home”. In other words, as per Simmons’ analysis that the provincial government

never embraced a “positive policy” in regards to people with intellectual disabilities, official avenues made institutionalization an easier option for many families, and reinforced the difficulty in keeping a child with a disability at home.

Part of a comprehensive understanding of issues surrounding parents’ decisions to institutionalize their children includes an appreciation of the variances in how different families responded to the bureaucratic ministrations and pressures of the day, despite similarities in socioeconomic status and familial situations. The reasons for the distinction between these two groups are complex and include psycho-emotional constructs, some of which are beyond the scope of this paper, as well as systemic factors. In general, the two women in this study who kept their children at home, Kip and Claire, felt they had access to the physical, social, and emotional resources needed to create alternative methods of care for their children other than the ones being presented by the predominantly medicalized and segregated care system. They emerged as women who were strong-willed, well supported in their marriages and families, willing to educate themselves about the political and social aspects of caring for their children, and were prepared to act on their behalf in order to effect change.

Both Kip and Claire stated that they and their spouses were in absolute agreement that their child would stay at home. Within their marriages, both parties agreed that institutionalization would never happen. As Kip remembered:

We decided we’re not going to treat her differently, she’s always going to be at home—that was the thing—Patrick [husband] and I had, we had the chat about institutions and whether that was [an option]... but I knew, and Patrick said—Never, ever, will I ever let her go to an institution. This is her

home; she's going to live here with us—So, that was out of our head. Institution was not in our head.

Indeed, both women claimed that the support of their husbands was instrumental in the decision to keep their children at home. As Claire explained:

I can't imagine getting rid of people because the system isn't adapting to them... I don't see how you can. I wouldn't have been able to do that; I wouldn't have been able to place Jay and neither would Vincent [husband]... I know I was very fortunate. I had a, my husband was, we were absolutely together on these things all the way through.

Further, the women who decided to keep their children at home were markedly committed to self-education about their children, about disability, and about the policies and political conditions preventing people with intellectual disabilities from engaging in the broader community in a just and equitable way. Claire, whose husband was a librarian who contributed enormously to her efforts to secure information about her son's disability, stated:

It's your job to read it... you have to read it. Vincent did all the finding, and I had to do all the reading; that's how I got started. I decided to start in the beginning, so I started with the history.

Claire believes that knowledge, and a commitment to act on that knowledge, are the tools needed to instigate real change, and that people's lack of engagement with information about disability and the policies that affect them are the reasons why improvements in the lives of people with disabilities remain painfully incremental. She states:

I was always amazed at how little people knew about disability. I was always horrified...if they understood why the attitude is what it is, and how long it's been like that, literally forever, I think they would be able to deal with it better... Most people don't know anything about disability. They assume the government is taking care of it.

These women used education as a tool to probe the system as it existed, and they worked tirelessly until they witnessed changes being made. Kip explained:

When it came time for me to look at schools, or to decide where to put this child to school, I had trouble then. And then I started to get busy.

Kip goes on to explain the first steps she took to establish a school which her daughter Theresa could attend:

It just kind of gets your back up...I said, I'm going to have to get a per diem for these kids. And I wrote a letter to the Minister of Education, and I got an appointment in Toronto, and I went by myself. I was brave as a lion when I think about it, because I was just quaking in my boots...but I did it, and it worked. And I got a per diem... I kind of knew how to write, and I was strong. And you get strong when you think there's an injustice. Injustice makes you strong... I was just in a rage. And there was no fooling around. I mean, they were all men, they were listening to me. And I said—I'm not leaving here

until I have a commitment from you guys. And I want it now.

And I'm starting this school. And I got it.

These women are aware of the commitment involved: "It's been work; it's still work. It never ends; it never ends". The above statements suggest that the women who chose to keep their children at home, besides benefitting from support within their relationships, had a clear sense of their own capabilities, and despite trepidation, enacted those capabilities against the constraints of a rigid bureaucratic system.

This emerges, therefore, as one of the key distinctions between those parents who decided to institutionalize their child, and those who did not. What becomes clear is that the decision to institutionalize a child had as much to do with how parents, particularly mothers, viewed themselves and their capacities, as with how they understood disability and its implications. While parents' understandings of disability were indeed relevant in regards to the decisions they made on behalf of their children and how they responded to the limitations of the system with which they were engaged, what is of equal importance is how parents viewed themselves, their roles as caregivers, and what they believed themselves capable of. Thus, while parents' interpretations of disability are vital to this discussion, and will be addressed in greater detail in a later section, it is equally important to examine social constructs which had a particular bearing on how parents, in particular mothers, regarded themselves.

Gender, mothers, and narratives of the self

Gender constructs particular to this era, as discussed in previous chapters, played a pivotal role in decisions to institutionalize a child with an intellectual disability. In particular, discourse concerned with women's roles and appropriate social locations created a limited field within which women could establish identity, seek meaningful engagement, and test their

capacities. Repeatedly throughout this research, some of the mothers described being told they were incapable of carrying out the demanding work of caring for their disabled child at home. This assessment came both from figures of authority who held respected positions in the community, and sadly, from the women themselves. As Louise stated repeatedly throughout the interview, “the doctor said that I wouldn’t be able to look after her”. This woman, despite deeply desiring to keep her daughter Harriet, her only child, at home, obeyed the doctor’s orders and had Harriet admitted to an institution. Moreover, in this particular case, Louise was completely dependent on her husband or his first family to go and visit her daughter. Although Louise had a driver’s license, she did not feel comfortable driving to the institution to see Harriet, or was not encouraged to do so, and thus could only go when others could take her. Thus, her entire experience of being a mother was framed by the understandings of what she and others believed she was not capable of.

Moreover, while some families seemed aware of the fact that the situation was indeed difficult for the mother and that limited options contributed to these difficulties, there was little critique within these families or within society generally in regards to how things might be done differently. For example, Bertram, quoted at the beginning of this chapter, believed absolutely that his wife was not capable of caring for their son with Down syndrome at home:

The basic reason that he went was that my wife couldn’t
handle him. And what was she going to do? She’s got these
three other children, and me, I’m not around that much, and
Michael [child] knew she couldn’t handle him.

And yet he offers no suggestion that perhaps circumstances could be organized differently, including his own role and presence in the home, in order that there might be actual answers to

the question—*what was she going to do?* This assumption that the difficulties in the home were located within the ‘problem’ of the disabled child and in the mother’s inability to cope with him is congruent with the gender and domestic arrangements of the time, arrangements which saw men carrying purposeful roles in the public sphere, frequently with long absences from the home, and women carrying the private roles of domestic responsibility. Moreover, there was little critical discourse suggesting that difficulties in caring for a child with a disability were linked to socio-cultural and systemic factors, and that more diverse domestic and labour arrangements might better serve the needs of all parties (Brookfield, 2012; May, 2008). Gender specifications therefore reinforced the difficulties that many of the women faced, and ultimately facilitated the placement of many children in institutions.

Louise in particular expressed an overriding sense of resignation to authority that she felt knew best what she was meant to do. When asked what she felt about her decision to place her child in an institution, she stated that she had never interpreted her decision as a choice, but rather as a something that was ‘meant to be’, and that she had not been coerced or influenced in any way.

No, I didn’t feel like that because....we prayed a lot and everything. And I just figured that the good Lord was going to have her go to the place that she was supposed to go.

This fatalistic perspective was compatible with acceptable gender and domestic arrangements of the time which left little room for critical analysis of current situations and how they might be altered. This is in sharp contrast to that expressed by Kip, above, who decided to fight the provincial government for education funding—*“I started to get busy”*.

In all of the marriages described in this study, men worked long hours outside the home, while women stayed at home in the roles of mother and homemaker. Mothers subsumed almost all of the care of the child with a disability in an environment of limited community and social support services. Claire described:

They provided this little pre-school, but it only went till six,
so when he was six, he came back; he was home again full
time. There was nothing else. There were a number of us in
the same situation, who didn't particularly want to
institutionalize our children, and that was the only alternative.

Moreover, it is important to note that the constructive changes which began in the 1970s to provide greater inclusion for children with disabilities occurred without significant threats to the role of men in both public and private sphere. That is, while positive change began to happen in the latter third of the century in regards to institutionalization practices and services for disabled people in the community, the position of men remained generally unmarked throughout—they maintained their role, their work, and their public face—and, in terms of domestic arrangements, the implications of these changes were felt more deeply by women, mothers, and people with disabilities themselves.

Moreover, inherent to the role of the non-working stay-at-home mother typical of the era was an assumption of support that she was expected to provide for her husband's work and public countenance. Betty described her need to have an ordered household so that she could host social gatherings, at the last minute if need be, in order to support the public facet of her husband's work. This was an environment in which she felt the presence of a child with a disability would be detrimental:

Well, we used to do a lot of official entertaining, because Owen was chief of the research department. So, when he got to a certain position, we were having dinner parties for these people who had come from Denmark or Australia, they tend to visit around, and they were rather official ones, and you had help putting them on, and so on. And it sounds silly, but I was fully co-operative in what his position was, and what that kind of entailed... So, we were having people from other central banks, and they would come to visit and so on, and we would be putting on parties for that, so it was easier, you know, I mean it fit in better with how our lives went... And we did quite a bit of travelling.

For Betty, the role of hosting official gatherings was simplified by the absence of Nora, her child with a disability, and allowed her to fulfil her obligations as a diplomatic wife without constraint.

Last, it is important to consider here the contribution of parents' expectations around the public image they were projecting of themselves. Drawing on Goffman's "dramaturgical metaphor" (Riessman, 2003, p. 7), Riessman (2002) suggests that people in public arenas "do not reveal an essential self as much as they perform a preferred one, selected from the multiplicity of selves or personas that individuals switch among as they go about their lives" (p. 701).

According to Riessman (2003), people "stage performances of desirable selves to preserve 'face' in situations of difficulty" (p. 7), and that we deal with conflicting identities by "resisting one and bringing the other to the fore" (Åkerström et al, 2011, p. 104). In a striking example which emerged from this research, Betty made explicit her desire to present a particular image of herself

in regards to her role as the mother of a child with a disability, or, rather, a particular image of what she was *not*. She was clear that she did not want to be “Mrs. Retarded [*sic*] Mother of the Year”, which, in her estimation, would have meant surrendering “my own life, in the style I wanted”. The heavy commitment Betty believed this entailed was not, in her words, “how I wanted to spend the next ten years”. While Riessman (2003) suggests that the construction and expression of self-narratives can go beyond the act of persuading an “audience” of one’s preferred self-image, and can actually assist one in “working over universal human problems—the purpose of living, the inevitability of dying—moral questions about life itself” (p. 8), Betty’s self-narrative seems, rather, to be about preservation of a particular identity in order to justify their decision to place their child in an institution, the injustices of which they were likely aware. The institutionalization of her daughter Nora fit the narrative that she felt committed to constructing for herself—the uninvolved and unencumbered wife and mother. Betty’s performative self of the independent and unburdened mother was essential to her, and she was committed to maintaining the self-narrative that she had originally imagined.

While Åkerström et al. (2011) support the importance of Riessman’s work concerning the subordination of one identity in favour of another in certain situations, they further suggest that some “cultural identities... may constitute parallel discourses, visible during the same conversation... as they go about making sense of their experiences and reproducing their identities” (p. 104). Accordingly, two parents presented what appeared to be parallel yet contradictory identities in a seeming effort to make sense of their decision to institutionalize their children. Bertram, who became heavily involved in the local parents’ association, described the work they did in efforts to improve conditions in institutions around the province.

We decided in the Association that we should be visiting as many of these places as possible as a group. And we used to go up to Orillia... I know they were crowded, but all it took was a little common sense...but anyhow, they went up and then Dymont [Minister of Health] sent them a letter. He was really put out that they showed up without telling people they were coming....So, anyhow, they started raising the dust, saying—this is absolutely atrocious. So, of course the papers start picking it up, you know.

The poor conditions that Bertram observed in the institutions he visited did not alter his opinion that they had made the best possible decision for his son Michael's care. Rather, he used what he knew of the other institutions in the province and their reputations for poor care as evidence that they had indeed made a good choice by sending him to a different facility.

Bertram: Then when we got to the parts of Orillia they didn't want you to see, it was absolutely disgusting. Oh, geez. Francine [wife] and the women got into, I think it was E block. The windows were broken and it was winter-time. The kids were sitting against the wall, just an undershirt on. And the snow's coming in and blowing across them... But Michael wasn't in Orillia...He was never in Orillia

Madeline: So you think Orillia was worse than some of the other places.

Bertram: Oh, it was. Oh, yeah.

Bertram's paradoxical stance, that is, believing fervently that conditions were indeed "atrocious" at Huronia, yet assuming that his son was not subject to similar conditions could be interpreted as a "performance of conflicting identities" (Åkerström et al, 2011, p. 104) which occurs "when non-preferred identities for some reason cannot be hidden or subordinated" (ibid). It seems that in the context of this research, the process of justification required by Bertram to cope with his decision includes the performative balancing act to which Åkerström refers, wherein one juxtaposes one's thinking against another which appears far worse, perhaps to avoid feelings of self-recrimination. This ambiguous position was expressed by Susan, who also spoke about her work to improve living conditions at the institution where her daughter Beatrice lived.

There were, it was an institution, there were a few, well, I
mean, many snags. I have a letter here that I wrote in 1965—
I'm writing to you in support of other parents who have
recently been helping to publicize the gross overcrowding of
patients. But in general...

Similar to the father quoted above, despite her awareness of the poor conditions of the institution where her daughter lived, Susan remained adamant that this was the right decision for her daughter and her family: "when Beatrice was eight, we made the decision to enrol her there, and never looked back". Part of these parents' coming to terms with the decision to institutionalize, therefore, seems to include establishing a particular identity, "situated and accomplished" (Riessman, 2003, p. 7) to negate a parallel yet simultaneously damning self-narrative.

Despite these examples of parents' performance of "two or more situationally actualized identities in parallel" (Åkerström et al., 2011, p. 120), and thus the sense that parents were participating in paradoxical yet simultaneous self-narratives, few parents in this study referred to

the idea of a secretive or double family narrative, a theme which had emerged with significant impetus from the siblings. This gap between the two groups will be addressed in the next section.

Family considerations

It is striking that the theme of a ‘double’ family narrative, one that had carried such import within the sibling group, barely surfaced with the parents. What this points to, perhaps, is not merely that the groups had different understandings of whether or not certain family narratives existed, but rather that each group experienced their implications differently. That is, the implications of a ‘double’ narrative, or one in which understandings around the existence and whereabouts of a sibling with an intellectual disability were presented differently outside of the home as compared to within it, were felt less keenly by the parents, whereas siblings experienced this differentiation profoundly. The parents in this study suggested minimal angst regarding presentations of family that might contradict the ‘real’ picture. For the most part, parents indicated that they felt that they had let sufficient friends and neighbours know of their ‘missing’ child, and did not dwell on suppositions that people might have had inaccurate impressions of their family. Owen stated, “We just... assumed it was normal. I don’t remember going to any great lengths to explain to the kids. I don’t remember that”.

His wife Betty added:

I never felt that they [extended family and friends] thought that we weren’t doing the right thing. It seemed to be, you know, in fact, somebody said—*Well, you know, it was nice you brought her home from the hospital*—because there was that option that I didn’t have to.

Susan further noted:

If a family is sufficiently open about their child, and that's what matters more than anything else—being open and accepting of the situation and of the person, it benefits everybody who comes in contact. All my friends, all my neighbours know Bea and accept her.

When asked about the impact that Beatrice's removal had on her two remaining brothers, Susan added:

Oh, no, they never [challenged] us. Never, never. No, no. It was simply accepted.

As discussed in Chapter Eight, however, several of the siblings felt that the need to navigate around the sometimes un-voiced existence of a disabled brother or sister, both in the community and in the family home, had a significant impact on them. The pain that many of the siblings experienced in this regard—not telling their friends about their institutionalized sibling, for example, or knowing implicitly that they were not to speak about him or her in conversation—suggests that this was an unwieldy social situation for them. While parents were in control of the narrative and could design its features and its praxis, siblings were left to determine how to shape and manage the narratives in a way that was livable from the perspective of a child or an adolescent. And while siblings spoke at length about their difficulties in managing the narratives, parents in this study referred to them only in passing, suggesting that this was not something with which they felt the need to invest a lot of energy. Moreover, those parents who were involved in their local associations frequently had social networks that included other parents of children in institutions. In those circles at least, there was less need to determine how to navigate situations of uncertainty or to share what might be considered awkward family

histories. While the parents had greater control over the people with whom they could associate, including other parents who had also institutionalized a child, a good part of siblings' lives was grounded in school and neighbourhood situations over which they had very little control, and they intersected with divergent circles of people without that shared history, reactions within which they could not reasonably predict.

There are, as always, some exceptions. Elisabeth spoke of learning that her son Steven, who had spent some time in an institution more than thirty years ago, had believed until very recently that his sister Fiona had also lived there. The unaddressed truth in this situation, brought to the mother's and sister's attention when conversations commenced in their home regarding class action lawsuits against the provincial government, indicated that family narratives were understood differently by different members of the family. In this particular case, the recent acknowledgement of different understandings of the family story has meant a painful re-writing of a narrative that Steven did not know existed. Fiona recalled:

Steven was talking and talking about [institution], and *this* (*demonstrates hitting*)... and then, trying every possibility in my brain of what could he possibly be talking about... and then I finally said—*Did you think I was hurt?—Yeah—did you think I was at [institution]?—Yeah*. And then I had to sit there and say—No, I was here, I stayed home... I got to stay home.

The experience in this family suggests that there are perhaps unaddressed narratives in all family situations, and that their truth is revealed when the family is willing to position themselves in a difficult emotional location in order to engage with past experiences.

Beyond family narratives, parents in this study also spoke to their experiences of decision-making around their child with a disability, and on the impact they felt these decisions had on the rest of the family. First, several of the parents indicated that the removal of the child with disabilities met a need for order and lessened disruption in the home. As Susan indicated:

By now Bea had two younger brothers, and she was becoming disruptive... the boys would perhaps have something spread out carefully on the floor, and she would come along and disrupt it, and it was difficult. It was difficult to integrate her into the household.

Betty stated

At one point, I thought—I can't have Nora home *over* Christmas, you know, the actual days... we had three kids at home and a large family connection, and it seemed to me that we were the ones who held things, you know, celebrations and so on took place at our house. And we did some entertaining as well, with Owen's jobs, so between the jigs and the reels, I didn't really feel I could do it all.

For Susan and Betty, the ability to run an ordered household and to host events in the home took precedence over the presence of a child who might be disruptive, or who might make some of their guests feel uncomfortable.

Second, some of the parents referred to the relief they felt when the child was removed from the home. Because parents described this as a generalized reprieve, it is difficult to ascertain precisely to what the relief should be attributed. One might assume, based on observations in

other parts of this paper, that the relief was based on both the simplification of their lives in terms of personal care, supervision, and the upkeep of the family home, and on the removal of the embarrassment of having a child with a disability and the need to continually address this anomaly in interactions with other people. When asked about her experience of sending her daughter away to an institution, Susan stated:

I think you have to be perfectly frank and say it was an enormous relief. I was sad, I remember coming home, crying buckets the night I took her, and of course, yes, the answer is I did miss her, but she had become, it had made family life stressful, and we just felt very confident that we were doing the best thing.

Betty also stated:

It was hard, but I was relieved to be doing it... it was a relief to me to not have her living at home all the time... I felt I would have found that hard... I felt that a lot of people were relieved that the situation had been dealt with in a way that was acceptable.

Interestingly, Betty also described her experiences of relief at several other points in the interview, usually in regards to the care of her daughter being assumed by someone else. For example, she describes her feelings when her daughter was discharged from the institution and went to live with another family:

She was part of a family group, and in a more normal situation, and I was greatly relieved...as far as I'm concerned,

that was a wonderful thing that they did for us and for Nora...I
felt good about that...and she was so happy.

Further, Betty expressed great relief that Nora's death happened after only a brief illness:

I was so relieved that she had a stroke and died five days
later. And I was so relieved that that's how she went, that it
wasn't going to be a physical and mental deterioration over a
long, long time, I mean, partly for my own sake (*laughs*)...I
must say that I had a sense of relief that it had all ended and
in a nice way, an acceptable way, you know...she had a very
short [demise].

In this particular case, Betty's reflections are bound tightly around the notion of being relieved of some responsibility that she felt incapable of assuming, albeit with mixed feelings. She was aware that as a mother, there was significant moral and social pressure to feel greater obligation towards her daughter. Yet she was relieved, first in knowing that "the other mother" had taken her daughter in and cared for her with attention and inclusion, and second, that any further consternation that she herself might suffer in relation to her daughter's life and its assumed complexities was alleviated when she died. As much as Betty was relieved that Nora apparently did not suffer greatly at the end of life, she was also clear that her daughter's death signified an end to decades of consternation that "I would fail in my duties to her...and I couldn't live up to what I thought I should do...to me, [her death] was the end of that".

Third, many of the siblings interviewed for this study expressed their impression that their parents had institutionalized a child in order to create what the parents thought would be a better home for their other children. Interestingly, similar to the discussion above concerning the

discrepancy in sibling and parental interpretations of family narratives, this was not a point that parents in this study brought forward with much consistency, except, perhaps, in regards to the notion of the child being a source of disruption. That is, while the siblings' impressions had been that parents' decisions to institutionalize was at least partly based on their desire to create a home that was geared to the non-institutionalized children's success, this was not a topic that figured prominently with this group of parents. Rather, parents' apprehensions were focused on other factors such as their perceived inability to care for the disabled child, disruptions in life style, and public embarrassment around the existence of a child with an intellectual disability. These factors, at least in the conversations contained within this study, took precedence over creating an environment conducive to the well-being of the other children. This suggests that much of the decision-making that parents made in regards to their son or daughter with a disability actually had more to do with their own personal concerns than those of their other children. Further, parents did not seem to consider that keeping the child at home might actually have proven, in the long run, to be a more fruitful and mutually beneficial arrangement for all their children.

This subtle differentiation in perspective is notable when one considers the reflections from Kip, one of the mothers who did not institutionalize her child:

Well, I think it's a deep love of that child, and wanting that child to be a part of the family. Because when they're in an institution, regardless of how good it is, how wonderful it is, and people will tell you it's great and everything—they still miss the love of their siblings. The siblings, I found, were totally in love with Theresa, totally in love with her... they never treated her differently, never. They were proud of her,

almost. And why we didn't send her to an institution? I think we just felt that—this is it. This is her place. She's in her, she's ours, we want to keep her as ours.

This mother is suggesting that had institutionally-minded parents been able to take the 'long view', a consideration of the entire family and its prospects for the decades to come in the family history, they might have decided differently.

Fourth in this section regarding family concerns, some of the parents brought forward the idea of institutionalizing a child in order to preserve a particular way of life. While this was not a theme that emerged from all parents, two did articulate it most definitely as a reason why institutionalization was the best option for their family. As Betty stated,

I was getting off easily, living my own life, in the style I wanted to... I was grateful to them [the institution], to have had, to have been able to do that, to live my life more normally, what to me was a more normal life.

Betty is honest in her appraisal of what the institution offered her as the mother of a child with a disability. And while she admits that she "had my own guilty feelings about getting off easily", her guilt seemed worth the burden to alleviate herself of a life that she admittedly did not want to assume. This appraisal is picked up by Kip. She reflects:

What were their motives for doing that? It's hard to say. I think in some cases, where there was lots of money, where the parents lived a different lifestyle. Our lifestyle was simple—we had children, we weren't going any place, we certainly weren't going on vacations—and I just remember

the children who were institutionalized, they were the children of people who lived at a higher level of income and status in society... You hate to classify them, but I know that some people put them away, and that's what I call it—'putting them away'—it was easier for them to live the lifestyle they wanted, without the appendage.

This is definitely a theme that was iterated by several of the siblings, who felt that parents' class-consciousness was a determining factor in removing the child with a disability. As one of the siblings, Pauline, had stated:

Looking back on my own experience—I think class has a lot to do with it. You know, if you're from a family like Mum's, you don't have a handicapped kid.... if they are middle-class, lower middle class, poor people—doesn't seem so bad, doesn't seem so outstanding. It's—Well, here's this person and we're going to get on with our lives. But I think class is a big player there. [There] were also people who were very well off, very wealthy people, who just didn't bring the kid home. They were, you know, all of that strata, and I think that, culturally, I think that had a lot to do with it.

Concerns that disability would threaten a family's potential social status and regard in the community are noted by Simmons (1982), who observes that families who petitioned their local members of government in order to gain access to institutional care during this time period were primarily of middle-to-upper class standing¹. Moreover, one of the parents (Susan), and three of

the siblings (Geraldine, Gregory, and Patricia) in this study referred to the British influence on a ‘culture of separation’ in which the norm was to send one’s child away to be educated.

Geraldine, who had one brother who lived in an institution and another who spent the majority of his growing-up years at boarding school, noted:

It’s also British. It’s that whole idea that you send, that it’s okay to get rid of your kids to be educated someplace else, they get their, you know, they’re provided for and there’s a social norm around that kind of separation. It’s quite bizarre, actually.

Accordingly, Susan described the process she and her husband used in order to prepare their daughter for admission to the institution by comparing her new “home” to the boarding schools to which members of their extended family had become accustomed in England:

It was like having a child at boarding school. In fact, we had gone, once we knew Bea was going to be admitted to [institution], which we had had confirmed in the summer of 1958, we all went to England on holiday. It was a great occasion, because it was the first time we had been back since our emigration. And my father, who was a master at a boys’ school in England—what you here you would call a private school, which we call public schools—so, we took Bea around and we told some of the boys the situation and they’d say—*Come on, Bea, we’ll show you the kind of place where you’re going to live. You’re going to live like we do.* And they

showed her their dormitories and things like that. So, we told

Bea—you're going to a boarding school.

Thus, for some families, placing a child in an institution paralleled an already-existing custom, tightly connected to British class conventions, of sending children away from the family to be educated, part of a culture of separation that was seen as a necessary step in becoming an autonomous and well-rounded individual, while simultaneously strengthening the class position of the family. The organization of Ontario institutions aligned itself with this thinking, using the nomenclature "Ontario Hospital Schools", a title meant to convey the institutions' promised educational potential and not only its custodial nature. Susan felt strongly that this was what institutionalization offered her daughter:

I realized that it is, or was, literally, a hospital school. They had an excellent school and many other facilities of an educational nature... It was an amazing place. It had every possible facility. It had swimming pools, it had gymnasiums, it had special equipment, it had trained doctors.

Susan believed fervently that institutionalization was to Beatrice's benefit, and that the institution would provide what she could not provide at home. What Susan deemed important for her daughter's upbringing—a sound education and specialized treatment—would be better met in a segregated setting, and took precedence over the possibility of family relationships and a life in the community. Moreover, accounting for her history and familiarity with the British system, this was a method with which Susan felt comfortable, unlike the prospect of having a child with a disability at home, which at the time probably presented itself as a vast unknown with few guideposts.

What emerges here, and as has been acknowledged in other areas of this research, is that parents provided hugely divergent interpretations of the care offered at provincial institutions. While Susan was adamant that the institution offered her daughter a sound education and an abundant lifestyle, Elisabeth, whose child was at the same institution, spoke of it only as “horrible, absolutely horrible... a snake pit, a hell hole”, and that the people who influenced parents to send their children there should be “burning somewhere”. Such vast discrepancies in experiences of institutions must be attributed in part to the psycho-emotional processes that parents have used in order to come to terms with their decision to institutionalize. The majority of survivors and siblings who participated in this research have made it abundantly clear that government-run institutions were sites through which the oppression of people with disabilities was maintained, both within their walls and within the public imagination. One can only presume, therefore, that parents who spoke highly of these same establishments have somehow reconciled damning reports of institutions with their own unwaveringly positive impressions, necessary perhaps in order to manage potentially difficult emotions in regards to their decision.

Thus, a strong inverse relationship emerges. The more highly parents viewed institutionalization, the less damaging they imagined the process to be for both the child who lived there, and for the rest of the family. As Susan explained,

I certainly never had any doubts about the decision because it was so obviously benefitting her... the impact that it had, that her absence had on me, was wholly positive, given who and what she was.

Conversely, when parents questioned their decision and felt more deeply the implications of having removed a child from the home, they saw this as more damaging to the family and the home. Elisabeth presented her perspective:

... labelling has had a profound effect on his life... the fact is that Steven had those experiences, as did all the other thousands of people, and the profound impact on their lives and their families' lives...

Rather than assume that these parents formed different impressions due to being exposed to different parts of the institution, it is probably theoretically safe to assume that varying interpretations can, at least in part, be attributed to parents' vastly different internal coping mechanisms. While analysis of the psychic underpinnings of these mechanisms are beyond the scope of this paper, the divergences in parents' interpretations serve as a reminder of the vulnerability of disability and of the services created to 'meet' the needs of people with disabilities to interpretive mechanisms and shifting discourses, often at the jurisdiction of those in positions of power or authority.

Finally, to conclude this section on family considerations, what emerges is the sense that parents' decisions to institutionalize were based on some point of fragility. Whether it was precariousness in the limited services that were offered to families, or a perceived lack in parents', particularly mothers' ability to care for their children, or a fragility in the marriages that were unexpectedly thrown into situations about which they knew little and often did not wish to venture further, what emerged from these interviews was a sense of something fragile or broken in what should have been a net of support around those families with a disabled child such that institutionalization would not be necessary. The trust upon which all sound communities are

built—trust in self, trust in family, trust in the government institutions designed to protect and enable its citizens—was absent or seriously compromised.

The point to consider here is where and how the fragility presented itself. Families that had reluctantly decided to institutionalize their child, with an awareness of the lack of services available to them and their own inability to care adequately for their child, experienced this brokenness within themselves, aware of the limits in what they could offer their child. These were the mothers who suffered the most; these were the fathers who became heavily involved in their local association to assuage the guilt of having sent their child away. Bertram described the horrible feeling that arose when they watched their son disappear into the institution the first time, an event that undoubtedly left a lasting impression:

When the staff came and took him by the hand and walked
away with him, they walked down this long hall, fading into
the dark, and my wife said to me—*I can't come back here.*
She said—*I can't watch that again. I just can't watch it.*

Those who were content with their decision and had unwavering confidence that their child was receiving good care tended to locate the problem within the child himself, that it was the child's high level of need which created the problem, not the lack of support. As Susan stated:

Obviously, I would have loved to have had a normal
daughter, and now the older I get, the more often I think this,
you know, wouldn't it be wonderful to have a daughter
looking after me instead of my looking after her.

Claire, one of the mothers who did not institutionalize her child was adamant in her assessment that the brokenness upon which so many of these decisions were made rests on gaps in policy

and services, and parents' unwillingness or inability to rigorously critique society's ongoing inclination to locate the problem within the disabled person. In her words:

I was always amazed at how little people knew about disability... It was not what they were interested in. They were very much in the immediate. But the immediate was the result of that history... the [seminars] that people come to are the practical—how to—not the whys and what's wrong with the system—not that. They like the immediate thing.

Claire further observes that the lack of analysis has moved even further into unwillingness to critique current methods of dealing with disability:

You know there's something fundamentally wrong in a society that people will abort—I don't have any religious prejudice here; I'm not a religious person—but people will abort, will take a life virtually, or a potential life, rather than fight for support.

Thus, despite decades of disability rights activism and awareness work, she points out that disability, for the most part, remains an embodied entity located in the person, presenting situations that parents would frequently rather address through eradication than agitating for changes in policy and attitude. This observation, as well as other comments parents made regarding the attitudes towards disability, will be addressed in the next section.

Disability and the precarious life

This chapter concludes with a brief reflection on the views of disability as expressed by some of the parents in this study. Most striking are the narratives of two parents who

institutionalized their children which closely parallel their current views of disability and the value of the lives of people with disabilities. Betty and Susan, given their own experience, remain convinced that there are certain lives which simply should not happen. Susan after learning that the tentative title for this dissertation included the sub-text ‘missing lives’, stated that in her estimation, the ‘missing lives’ do not have to do entirely with people who ended up living in institutions, but are, rather, those with more severe and profound disabilities who should not exist in the first place. In her words:

There were wards at [institution] which would break your
heart, the children, unknowing children, little lives who, well,
I mustn’t get on to my other *bête noir*, which is the fact that
there are a lot of people who are alive who shouldn’t be.
Little lives that should never have been kept, who would have
been happier in heaven than on earth, you might say. So,
there were people like that; *those* were the missing lives.

Susan’s estimation regarding the value of people with significant intellectual and physical differences contextualizes her decision to place her daughter in an institution. And while she feels that Beatrice has had a full and happy life, she is not so convinced that all individuals should so readily be offered that opportunity. Betty, also honest in her assessment of her feelings towards her disabled daughter, said:

I know, and I hate to say this, that if they had had
amniocentesis in those days, the way they do kind of
standardly now, I think, and had that been the diagnosis, I
would have aborted... I enjoyed parts of Nora, but it was not

to me a great pleasure...So, no, I, to be honest, I mean, I know that sounds terrible, but if it had never happened to me, I wouldn't have missed it (*laughs*).

Betty is honest in her admission that the unexpected invitation to be the parent of a child with significant differences was a role she did not want and never really did embrace (her daughter was institutionalized at age two). Betty admits to having “faked a lot”, suggesting that she presented a public face of a woman content with her life and the decisions she had made. As she explained, describing the role her husband had assumed, “Owen was much better about it than I was; he played it more” —seemingly, that her husband played the role of the involved and concerned parent better than she did. Underscoring all of this, however, is her observation that she would have been just as content if none of this had happened at all. Thus, the relief that institutionalization offered was a replacement for a more fundamental relief that might have flourished had her daughter not been born in the first place.

These positions contrast sharply with those of parents who chose not to institutionalize their children. As Kip stated

You have another role to play. It's not the role you planned for yourself at all; [but] it's a role that's going to help a lot of other people. I kept always thinking, the more kids I would see, the more I'd say—Yes, I was right. I'm on the right track. Go for it.

In reference to her daughter, she adds:

Well, we had her for twenty-five years. She made us all better people. I mean, she made us know what it was like, to, you

know, have somebody around you all the time who, who was just not perfect...she was a lovely, beautiful child...it was a hard thing at first, but it made me so strong.

Claire, another mother who did not institutionalize her child, put it this way:

Life has been for us far, far richer, far, far, more rich than it would have been if Jay hadn't been born. I mean, there's no doubt about that whatsoever.

Moreover, these mothers also noted that institutionalization, in its inherent inflexibility, prevented parents from experiencing shifts in understandings of disability, as slow-moving as they were, that might have allowed them to revise their view of their children, their needs, and their possible contributions. Once a child was placed in an institution, parents were removed from circles that questioned perspectives and interpretations of disability, and for the most part, any political will they might have had to make systemic changes was diminished.

And thus herein lies a fundamental observation from this study. For parents who institutionalized their children and who saw the problem of disability as residing in the child, there was little impetus to try and alter political and social structures that prevented them from meeting their child's needs in the home or the community. Parents who kept their children at home, however, attempted to understand their children at a level other than a problem, and generally worked to change the way in which the world met and interacted with their child. As Claire noted, the energy devoted towards altering oppressive systemic structures had the potential to spill over into a more inclusive world for all people with disabilities:

Right from the beginning, it [institutionalization] didn't seem to me to be a solution. You don't, you don't send your kid

away... it's always been big issues, and you can't do it just for him... if you fix the big things, he gets fixed, but then so does everybody else. And that's the way it should be in any society, in my opinion.

In conclusion, findings from this chapter suggest that decisions to institutionalize are reflective of more than concerns around family, lack of support in the community, and lack of knowledge about disability. Parents' decisions to institutionalize are also reflective of deep-rooted understandings of disability as an individually located problem best solved via the unquestioned offerings of an efficient political system, rather than imagining that something more just might be possible. Further, comments above suggest that struggles to counteract inertia around points of potential education and activism remain, and that there is still work to do in defining disability as something other than a problem.

Chapter Ten: Findings, former staff

Introduction

This chapter addresses findings from four interviews conducted with former staff of one of the Schedule 1 institutions for people with intellectual disabilities in Ontario. Two of the staff were women; two were men. Despite the small number of former staff interviewed, they had a combined total of almost one hundred years of employment in the institution. All of the participants in this group reside in the town in which the institution was located, and three of the participants also grew up there. Thus, they feel a strong connection to the institution, both as a place of long-term employment, and also as a historic and geographic landmark which has played a significant role in the life of their home community. This connection will become more evident in the coming pages, as it is clear that working at an institution over a time period which spans several decades has had significant impact in the lives of this particular group of people. As the institution was officially closed in 2009, all of the participants in this group have since found employment elsewhere, all in postings closely related to the work that they carried out at the institution.

Former staff were interviewed to obtain their perspectives on the principal themes of this study, and to gain some understanding of institutionalization from a perspective that was embedded within its organizational and hierarchical milieu. Accordingly, three principal themes emerge from the findings in this group. First, in accordance with the principal objective of this study, staff perspectives on family relationships and understandings of disability are addressed. Staff held what might be seen as privileged positions in this regard, as they interacted with the residents of the institution in intimate and vital ways and wielded significant power in those relationships, yet were not responsible for sorting through the complicated and emotionally laden

processes which had led people to be institutionalized and which coloured family relationships with institutionalized individuals. Second, staff addressed at length the phenomena of institutionalization and deinstitutionalization, primarily from the perspective of persons deeply engrained within the institutionalization system, who viewed institutions as a necessary and ample method of caring for people with intellectual disabilities, and who held deep concerns about their closure. It is important to note at this point the primarily positive perspective that former staff brought to their observations; these are people who willingly chose to work in an institution, and would have remained there had the institutions remained open. Further, their willingness to speak with me, despite criticism currently being directed at institutions in Ontario, reflects their relatively unambiguous position regarding what they perceive to be the benefits of institutional care. Throughout this section, a complex psycho-emotional picture emerged which suggests that participants' reflections about care for people with intellectual disabilities, including the possible return of institutions, were tightly interwoven with personal concerns about their relationships with former residents, and in their own careers as caregivers. Accordingly, this section includes my own observations as researcher that the staff who participated in this project, formed as caregivers in a highly regimented system, tended to articulate their insights from a position of immediacy and proximity both to the people with disabilities with whom they had worked, and to their own roles as caregivers. This proximity to and investment in the daily intricacies of the institution, including their own sense of belonging in a highly specialized community, seemed to act as a barrier to a broader perspective wherein deinstitutionalization is considered a necessary if sometimes difficult step in the establishment of an ultimately more just and inclusive society. Moreover, the position of emotional immediacy seemed to facilitate a sense of loss, a theme which emerged consistently from the text, especially

in regards to institutional closure. Last, the chapter concludes with some comments from former staff which indicate that in light of their overwhelmingly positive experiences of working at HRC, and despite its complicated and not uncontroversial history, were the institution to return, they would gladly resume their former positions of employment.

Perspectives on families: Emotions and authority

As mentioned above, the four staff interviewed for this project had a combined history of ninety-two years' employment at Huronia Regional Centre (HRC), lending credibility to their observations of family relationships as lived through the interface of the institution (Clarke, 2006). Moreover, their duration of employment—one woman, Sarah, worked at HRC for thirty-one years—provides a lengthy lens through which to observe changes in institutional practices, including space, language, and priorities, and offered perspectives on differences in family relationships depending on the era during which people were committed to the institution.

In general, staff noted that the majority of residents of the institution did not receive visits from families. Wanda described it as a 'sliding scale' in terms of the frequency of visits:

I would say maybe twenty percent of clients had close family interaction. I would say another twenty percent would have periodic, maybe letters, phone calls, maybe see their family once a year, but the rest, it was just a sliding scale down and there were quite a few who never, never heard, never saw, never knew.

Staff noted that the frequency with which families visited was primarily determined by when the person had been admitted to the institution. Those whose families did visit had generally been admitted to the institution later in its history, when it was more common for families to remain

connected and involved with their son's or daughter's care. It was these families with whom staff had the most connection, and with whom they had some kind of working relationship.

Conversely, there were residents who had been institutionalized at a young age, had lived in the institution for decades, and had had virtually no contact with their family from that point onwards. Most of these residents were elderly, and several had no surviving relatives with whom he or she was in contact. As Rory pointed out:

[They were] certainly older... they'd had very little contact with family because they didn't have parents, and siblings weren't as interested, in some cases, as parents were. And some of the older people who had been there for fifty or sixty years, I mean, they were put there through the CAS years ago, because they were Crown wards, so they might have had contact with no family members.

This 'lost generation', as participants referred to this particular cohort, surfaced as a point of discussion several times during the interviews, and were of primary concern for participants, particularly around the outcome of deinstitutionalization, which will be addressed in greater detail below.

Observations from former staff thus serve as a template of the history of the institution and the policies being enacted during particular time periods. For example, all of the staff noted that, in their opinion, there were residents at Huronia who "should not have been there". These included those who had been relegated to custodial care via legal channels such as the Children's Aid Society because of ubiquitous eugenic concerns in the first half of the twentieth century regarding 'feeble-mindedness' and its potential to spread if certain segments of the population

were not segregated. Sarah, whose father had worked at the institution before her¹, described what he had told her about a train from Toronto that ran directly into the grounds of the then-named Orillia Asylum for Idiots, depositing young, sometimes parentless and lower-income youth into the confines of the institution, usually never to leave again:

A lot of them were misplaced, because [my dad] said he can remember when, because the train tracks ran right through the grounds, like, by the beach, and he said he can remember trainloads coming up of children that were misplaced; they didn't have anywhere else to go. And it wasn't like they were, they might have been slow, or economically, they couldn't afford to be on their own, but they were in, they were maybe, there just wasn't any place to put them, so they sent them there.

As Joe, one of the male staff noted, this was a trend that had had a significant influence on the population of the institution. He observed:

There [were] a lot of guys there that didn't belong in a big institution. Guys, really high-functioning guys who just didn't belong there, who didn't have behaviours, would have done great in the community, but they grew up there.

Thus, familial connections were a mirror of the time period during which people were institutionalized, and demonstrate the fluctuating nature of understandings and interpretations of disability. Former staff, who now witness the possibilities for people with intellectual disabilities living in the community, recognize the profound disjuncture between current understandings and

what was previously deemed a guaranteed entry to long-term custodial care. Rory, who had access to residents' files dating back decades, stated:

I can go through a hundred files and you'll see—*Doctor at Sick Children's Hospital in Toronto recommended 'institutionalize immediately; institutionalize immediately'.*

That happened over and over and over again... As resources changed and improved and became available, families said—*Well, geez, why can't he live in a group home?*

Joe referred to an era during which it was common for parents to be told by institutional officials that they did not possess the skills needed to adequately raise their child, a task that was better left to professionals. He noted:

I think the approach fifty years ago was—*You have a developmentally delayed individual; you can't care for them properly, this institution/ hospital/ school can care for them. I think it was the norm...Were they discouraged from coming?*

I think they were probably—just leave them.

Former staff also spoke of the changing nature of relationships with family members over time. Rory referred to the loosening of bureaucratic boundaries as the decades passed, allowing families to have greater contact with their institutionalized child. In his words:

I would say initially, and I'm going back a long time ago, when they first admitted their family member to the facility, I would think the relationship was very... very cold, professional, like because you always had to deal with the

superintendent. Like, they had to write a letter to the superintendent if they wanted to come visit. So, because it was a very rigid organization, the families fit into the rules that the facility decided upon around visiting and the time, and all those kinds of things. And as time went on, it shifted where the families would just call directly to the living area and talk to the counsellor, or talk to, they would just say on the Tuesday—*I'm coming up tomorrow*—no problem. Or, not even call, just show up, and that was okay too. So, I think they felt much more welcome, much more a part of it in the later years.

Rory's observations suggest that the gradual release of hierarchically-informed relationships led to a more equitable sharing of responsibilities towards people in institutions. However, despite greater ease in communication and more frequent opportunities for shared decision-making, the overall authority for institutionalized individuals' care remained embedded in the institution (Simmons, 1982). As such, relationships between staff and family members were complex in regards to who held power and influence, and who maintained both formal and informal decision-making authority. Although families had relinquished their child to the state via the institution, and thus did not officially direct his or her care, there remained a complex dynamic of authority and emotion with which all parties had to grapple.

For example, Rory suggested that many families felt "beholden" to the institution "because the facility was caring for their son or daughter". In his words, "they deferred to the facility—you're the doctor, you're the facility, you know best". All of the other participants

referred to this deference, often manifesting itself as a complicated embarrassment in families' recognition that the staff knew their family member better than they did themselves. Add to this the pervasive guilt that many families experienced because of their initial decision to institutionalize, and there resulted a potent and ambivalent mix of emotions. Wanda described it thus:

So, the guilt... I'm thinking of one lady in particular, her family couldn't care for her any more, and that [the institution] was the only option they had... So, when they would come to visit her, there was a sense of—*we should have been able to do this for her*—but, however, the gratitude they had because they saw how loved and cared for she was, and that actually, she probably was better off, because she was surrounded by people who absolutely adored her. So, that was very, very... helped them to be peaceful about it.

While the principal timbre of this excerpt seems compassionate, it also reveals the complexity of emotions and understandings of authority that permeated many of the relationships between staff, residents, and family. What the staff identify as a family's gratitude might be better understood as something far more complicated, part of an emotional web with conflicting sentiments, and it is not clear whether or not the staff's conviction that the family was grateful was helpful to them, as they were already struggling with their decision to institutionalize. Wanda further suggested that parents' effusive demonstrations of gratitude were indicative of a pervasive sense of guilt. She described her understanding of this complexity:

My sense is that what was more important was, maybe the people who were very demonstrative of the gratitude, maybe that was an indicator that there was maybe some guilt, and perhaps some, maybe it started out as guilt but then the negative shift into the positive is, you know—*but look where she, you know, that this has taken place*—so, those, there's people who were enormously grateful, and always, like, they would send money for a party for the whole ward, and presents for everybody. So, they would show whatever they could do, but I wonder, you know, it could be, initially there's guilt, but there's gratitude attached.

Her assessment suggests that parents' emotional responses to both their children and staff were indeed a complicated mix of guilt, gratitude, and indebtedness. As such, part of the role of staff was not to judge families' actions, but rather to accept what advances they made in regards to their institutionalized children and to reassure them that their children were receiving adequate care. Wendy added this account:

This one young man that I took a shine to, his mum would come up maybe once a year and it was obviously excruciatingly painful for her... I think that she was still grieving and wasn't able to cope... it was very, very painful for mum... When she would come, I felt that I was there to support her (*laughs*) and to try to make her feel comfortable, that her son was being well looked after... not to feel guilty.

This sentiment, that staff were there to reassure parents, and that their children were receiving the best possible care, was echoed by all the participants.

All of the staff referred to what they determined was a general appreciation from families for the care their child was receiving. For example, Joe stated:

Most parents were very appreciative of the staff, and of the work they do, because they saw the types of guys we worked with, that were tough. And behavioural sometimes, you know, they knew they couldn't maybe deal with that at home, so it was mostly appreciative, very appreciative.

However, participants also mentioned parents who were, as one man described, “difficult”, that is, those parents who were not afraid to make demands on behalf of their child. Rory commented:

We had parents who—they knew best because they were the parents and they made sure we knew that every single time we dealt with them—*You will do as I say, because I'm the dad, and I know best.*

Joe added:

You'd hear about the difficult parents... [they] could be very demanding. You'd hear about them, and they were not necessarily the ones that visited a lot, but you'd hear stories—*Oh, so and so came and was very difficult.*

It is interesting to note that within the confines of a hierarchical and medically-based system, parents who advocated with persistence on behalf of their son or daughter were deemed

“difficult”, as they challenged the treatment and living conditions experienced by their children under the auspices of medical and administrative authority. Further, while it is tempting to characterize parents’ complaining as an unwelcome and unnecessary aspect of residents’ care, it must be contextualized within parents’ inevitable experience of tension in knowing they have seconded the responsibility of caring for their child to someone else, a tension that, as long as their child remained in the institution, remained irreconcilable.

Staff and family secrets

While staff envisioned themselves as carrying a facilitative and mediating role within families, their observations suggest that they also frequently acted as reservoirs for information that was not common knowledge within the family. Staff’s seemingly neutral position within the web of family history and emotion, as well as the circumstances of their employment, meant that they were frequently positioned as receptacles for difficult family information, and they stored hidden family details. In particular, participants reported the not-uncommon occurrence of adult siblings learning of the existence of their institutionalized brother or sister much later in life, often when parents passed away, or as deinstitutionalization gained momentum and living relatives needed to be located for those people who were about to be placed in the community.

As Sarah observed:

Once they [the siblings] did find out, they were curious, and how they found out, if it was after the parents died or whatever, that they found out, or you know, when the government was looking for some sibling or relative that, and wherever they lived, to place them in the same area as they were, sometimes that’s when they found out.

For staff, this was an awkward role to carry, as it meant frequently being present to conflicted, emotional reactions. Sarah continued:

When they found out? Boy, I don't know. I suppose surprise that, and a little bit of horror that the parents would have done that to... you know, just kind of disowned them, almost. Because there were a lot of people, parents that never visited; it was like a closed chapter for them.

Rory, who carried an administrative position and thus communicated with large numbers of family members during the deinstitutionalization period, described one contentious situation:

I can think of another situation where a family had placed their son there, and only by the grace of God, things worked out and they were always available, because they never told their other daughter. They told their daughter that her brother had died at birth. He didn't die; they admitted him to the facility. Forty years later, her parents died, and she was going through their papers and came across a document that said she had a brother at the facility. So, she called me... they had listed her as a secondary contact without telling her... So, anyway, she came to see me and she had a ton of tears and ranted and raved and hollered and screamed. It worked out okay... there's an example of somebody who had no idea.

One last example, also given by Rory, reveals how staff were compelled to hold in secrecy the true narratives of particular family situations, narratives that were not known beyond the doors of the institution:

And there were a few like that, these secrets. We had another case where the mother wasn't married, so she never told her family she'd even had a baby. And for her whole life until she died, she came to visit him once a month, and she had never married, and we all had to call her 'Miss', and she finally, when she got very elderly, she told a nephew that she had a son at Huronia, because he called me when she died and came to visit me, and brought me her will, and explained to me who he was, and then he carried on the relationship. But he was the only person in her whole family who knew she had a son, because—*Oh my God, he was illegitimate, that couldn't happen*. So, yeah, she admitted him and then she came faithfully, every month. The darling that she was, and she, but, again, her family had no clue.

These stories suggest that staff were participants, albeit with little control over that participation, in the perpetuation of untrue narratives that existed in many families with an institutionalized family member. As employees charged with upholding the confidentiality of arrangements which had led to individuals' institutionalization, they were, willing or not, witnesses to painful family narratives and their sometimes traumatic unfolding. Even if staff had felt morally compelled to disclose information that they felt should be revealed within the family, they were

never authorized to do so, and were obliged only to carry on with their primary task, which was to provide care to the residents of the institution.

Staff as family

As those who acted as reservoirs for intimate family details, and who were responsible for all aspects of residents' care, the claim from staff that they felt themselves to be the residents' family is understandable. Within the context of the institution, the interdependence between staff and residents—that is, residents were, quite literally, dependent on staff for their survival, and staff were dependent on residents for their livelihood and status—paved the way for a re-defining of 'family', such that the characterization of relationships between staff and residents as family was normalized. This was emphasized repeatedly in several of the interviews. In particular, Wanda noted,

It was just like a family, except the parents were staff members... [for those who did not see family members], we, their family was where they lived...we knew the client better than anybody.

According to Wanda, staff's emotional connections to residents, including a "sense of pride" in residents' accomplishments were "family; that's family stuff".

In light of the intensity of life in a closed facility and the shared nature of so much of institutional life, this sentiment is certainly understandable. Yet, from an observer's perspective, such statements are troubling and point to issues of power and control which are embedded in the very foundation of institutional life. As much as Wanda felt that the nature of her relationships with residents allowed her to categorize them as 'family'—and indeed, she may have given kinder and more considerate care than the actual families of some of the residents—

she remained in a position of authority over all of the residents with whom she had contact. If, for personal or relational reasons Wanda formed strong bonds with those who lived inside the institution, she still had the power to define those relationships, to intensify them, or to walk away from them as desired. The institutional residents, on the other hand, did not have nearly as much choice in the matter, particularly in light of their dependence on staff (Goffman, 1961). This finding is affirmed by Jones (1992) whose research with former HRC residents found that “the power to exercise real control rested (uneasily) on the shoulders of the counsellors and staff” (p. 343).

The danger here, again, from an outsider’s perspective, is that within these complicated emotional matrices, vulnerable people were implicated. While naming relationships as family might have been a simplistic but well-meaning gesture in light of the absence of so many of the residents’ birth families, it remains problematic that staff felt that they could define relationships as family, when clearly they were not. Or, rather, even if strong bonds were established between staff and residents and a sense of community was encouraged, it remains troubling that the authority to define relations as such rested solely with staff (Jones, 1992). Possessing little social capital in any exchange with staff (Bourdieu, 1990), nor in the outcome of their own histories, residents were subjected to the definitions of ‘family’ given to them by those with whom they had the most repeated contact. Of note here is that survivors interviewed for this study did not refer to any other residents or staff members as ‘family’, suggesting a disjuncture between the interpretations accorded to various relationships within different groups of people in the institution (Clarke, 2006; Reaume, 2000). Those with greater ‘social capital’, it seems, had greater flexibility and control in the categorization of relationships, a semantic authority that must have been disorienting and indeed troubling for those not doing the ‘naming’.

Moreover, it is difficult not to speculate in regards to the motives that staff might have had to define relationships within the institutions as family. Wanda, quoted above, appeared overcome with grief over the loss of her work in the institution and her ‘family’ there. The depth of her sadness was profound, and she mourned in particular the ‘lost generation’ mentioned earlier: those who had lived in the institution for decades, whose family were deceased or had not maintained contact, and who had lost touch with most other former residents and staff when the institution closed. While her grief was no doubt genuine, it appeared that her sadness, and the intensity of her feelings towards residents, was preventing her from seeing beyond her immediate experience of loss, and entrapped her in a small social and emotional space wherein the relationships as defined by the institution were seen as so central and vital that they excluded the possibility of new, organic relationships that might be forged outside of the institution’s walls.

Wanda’s depiction of the loss of her ‘families’ was articulated in particular in reference to the closing of Huronia Regional Centre in 2009, along with all remaining government-run institutions. The deinstitutionalization process, which included a gradual and lengthy reduction in services and the eventual closure of facilities, was met with ambivalence by the staff who participated in this study, an area which will be addressed in the next section.

Deinstitutionalization as loss; institutionalization as abundance

All of the former staff interviewed for this project felt that the closure of segregated institutions for people with intellectual disabilities was not necessarily a good solution for the residents who had lived there. Far from the persistent call from community living advocates that institutional closure was essential to the long-term vision of equity and inclusion for people with intellectual disabilities (although there were dissenting opinions within the community living

movement), the participants in this study were in almost unanimous agreement that segregated facilities remain essential for some people, and that the closure of Ontario institutions has resulted in an unwelcome reduction in services.

Joe described residents who he feels benefitted from the locked and segregated wards in the institution, established for particular groups of people. He described these people as “having behaviours”, which, I came to learn, implies the possibility for aggression:

[They were] very institutional in that sense, right? And you know, had some pretty intense behaviours... people were in certain areas... those wards still existed when I left and when they closed.

Currently working at a group home in a rural environment, Joe reiterated his perspective that certain people should remain in locked, segregated facilities:

The kinds of clients we have right now, some of them could be better suited to an institutional setting, for sure....where are we putting them instead? Are we going to put them in jail?... They need a locked facility.

He continued:

So, where do we put people like that, right?... Severe behaviours, like *severe* behaviours... [Deinstitutionalization] just doesn't always work for everyone... there's still some pretty difficult clients out there... and there's not the resources there, right?

Rory, while more optimistic about community living in general, spoke specifically about the impact of deinstitutionalization on people who have been categorized as ‘dual diagnosis’, that is, people who have been given diagnoses of both madness and intellectual disability:

I think community living is a great option for some people.

And for some people, they continue to struggle, and they don’t do well, especially sometimes people that have a dual diagnosis.

These participants seem to suggest that the most effective way to meet the needs of particular groups of people, especially those seen as bearing the potential for aggressive behaviour, is through the continuation of segregated facilities. That is, rather than approaching the issue of inadequate support by agitating for increased services and supports for families, their perspective, as former staff in a locked facility, is to re-invigorate a segregated, custodial model. While the continuation of locked facilities certainly seems the simpler route for many parties, as it ‘solves’ the vexing issue of meeting the oppositional needs of both people with particular impairments and a fearful community, it leaves little room for attempts at community-based alternatives that community living advocates had at the very least, imagined as possibilities for all people who had lived in institutions.

Similarly, former staff felt that institutional closure was not met by a corresponding increase in community services for people with intellectual disabilities. Their assessment is that residents’ needs were completely and consistently met while living in the institution, and that their leaving meant an abrupt cessation of the amenities available to them through the auspices of government-funded custodial care. Joe put it this way:

They have the same peer group. They have a pool, they have a gymnasium, they have a kinesiology programme, and let's face it, you go into the community, and not always do those things continue.

Sarah stated:

We always thought that maybe it wasn't the fairest thing, because the residents lack[ed] for nothing, other than, you know, we always thought if they moved into the community, they wouldn't have the resources available that they did at HRC. Like, the programmes and the swimming and the opportunities to do things.

Further, staff expressed concerns regarding former residents' access to good personal care and medical services. Wanda described seeing a former resident on the street in Orillia after the institution had closed, and indicated her displeasure:

He wasn't clean-looking any more, whereas before he used to be perfectly clean, well-dressed. He looked like a homeless person. He wasn't dressed properly in the winter time for the cold. And he was lonely... there's a lot of people who just kind of got lost, and they're out there.

The two men interviewed for the study recalled the ease with which the institution provided on-site access to medical care. Joe stated:

In an institutionalized setting, you just have more checks and balances and capabilities of nursing and all that kind of thing.

He went on to suggest that ready access to a highly medicalized system is most beneficial for managing severe “behaviours”, or to address the needs of residents with more complex disabilities:

I mean, when you’re dealing with intense behaviours, it’s nice to have a lot of staff, right? Like, it’s tough here [current work situation]. If three staff can’t deal with it, we have to call 911. Where, in a big institution, you had that. You had that medical consistency, too, so if someone’s having a behaviour, you could have a nurse give them a sedative...you know, for difficult clients, or severe, medically, fragile clients, for behavioural clients, it wasn’t a bad model at all.

The above statement, while chilling in its implications of lack of consent and disregard for human rights, illustrates the cognitive framing that staff used in order to justify the use of force, including forced use of medication, in order to maintain institutional order. Thus, although staff framed the institutional model as a site of consistent and ready access to medical care, it might also be interpreted as a system which facilitated the application of the more rigorous and oppressive arms of the medical model to maintain a regimented and organized environment with an unruly population. Joe also identified the institution, with its concentration of services and professionals, as an economically viable system:

That’s where a big place works. That’s where you do economies of scale. If you have nine staff and nine residents that are all one-to-one, what are the chances that all nine clients are going to be upset at once, right? So, that was the

great thing about a larger institution, right? You could have two staff working with eight people; you could have one guy working with eight, but right across the hallway, you have another guy, and right down the hallway, you know? So, you could call for assistance; we'd have pagers, and you'd have ten people running for one incident, right? So, it's for really difficult, behavioural, medically fragile [people].

Joe's observation on the economic viability of institutional care, that is, its ability to serve the medical needs of thousands of 'medically fragile' and 'behaviour-prone' individuals in a condensed location, is reminiscent of Goffman's (1961) suggestion that one of the fundamental goals of "total" institutions was "the handling of many human needs by the bureaucratic organization of whole blocks of people" (p. 6). Moreover, it reiterates what Simmons (1982) calls the "administrative economies" (p. 32) of large institutions, one of the fundamental historical justifications for the development of a custodial model of care which was massive in its structure and application.

Last, former staff remarked that the closure of institutions resulted in the loss of social connection and community for people who had lived there. This was described as one of the principal disadvantages of deinstitutionalization, a critique which carries significant weight within circles critical of deinstitutionalization because of its moral and ethical overtones. Sarah stated:

You know, we'd see residents who were already out in the community, and they would just be standing on the street, and that really bothered us because that was their community,

and that's where their friends were, and sometimes that's where their friends were all their life... they were being whisked away to somewhere they didn't know, people they didn't know, staff they didn't know. And their friends were gone, like, all of a sudden. So, it was hard on them, I think, that transition... to have all that taken away. It was a shame, in a way.

Wanda's depiction of the traumatic endings of relationships due to institutional closure also provided an image of their inner workings:

It was like a town. It was like a community... and it really... and you know it's so hard because we kept saying to people, and to the media, you know—this isn't always the best thing, is to take people and—I mean, they've grown up together; they're family. And now you're sending, you're splitting up these two best friend who have been best friends all their lives—one's going to Hamilton and one's going to St. Catherine's. And people who had grown up and lived in a large family group, and you know, they had their best buddies and whatnot, and when I see them in town, and they're living in a group home, they have a bedroom, or they're living on their own—now have nobody.

Thus, staff repeatedly framed deinstitutionalization as a loss, as a removal of services and connection which had enriched institutionalized individuals while living a segregated life.

Conversely, staff consistently offered the perspective that institutions offered a full, well-connected, and meaningful life. They suggested that within the institution's walls, residents experienced "freedom", "options", and "privileges" that would be difficult to replicate in the community. For example, Rory proposed that people who use wheelchairs generally had more freedom within institutional boundaries than they do in current community settings:

We had a number of gentlemen who had electric wheelchairs, and one man had one he operated with his chin. So, he had full run of the property; we had hundreds of acres. Because the rule at the facility was pedestrians and wheelchairs are number one, so vehicles—slow down and stay out of their way. So they had free run; they could go anywhere they wanted. And the entire facility was connected underground, so they could go for a couple of kilometers underground. So, then we're going to take those same people and move them to a street, beside you, and are they going to be able to go all over the place? I'm not so sure. So, I think their ability to move about is somewhat limited and restricted.

Sarah described the social programming that went on within the institution as an example of the wealth of opportunities available to residents:

We were always with them and doing activities for them. They were always kept pretty busy at whatever, and busier probably as programmes arose... they had an indoor swimming pool built, and they had day services, and the

residents would go to a workshop and they were always kept active, doing... they were always going on bus rides here and there, and going out into the community... there were so many options for them.

Thus, according to staff, the institutional model of care allowed the physical, social, and emotional needs of residents to be fully met in a fulfilling and efficient way. From an organizational perspective, the custodial model appears justifiable, preferable even, to a potentially more chaotic and disjointed system within the community. Moreover, the intense living arrangements—thousands of people living in extreme proximity—was not necessarily seen as harmful, but rather as a rich resource for relationships and community.

Critical analysis, however, highlights the weaknesses inherent to this model. Regardless of how efficiently a custodial model meets individual and communal needs, there exists a fundamental injustice towards people who have been segregated because of difference. Within this study, staff perspectives that people's needs were being met with a bounty of medical care and attention seemed to emerge from a narrow lens which focussed on the benefits of an institutional system, without acknowledging a broader perspective which includes the human rights and dignity of all people. Staff interviewed for this study generally did not contextualize their impressions of institutions beyond their own positive experience. They did not consider that underlying this highly efficient and 'privileged' arrangement lay a fundamental disregard for people's freedom and their right to be recognized as someone who does not require segregation in order to live a full and meaningful life. This perspective disregards the fact that, regardless of how good the care was in the institutional environment (and testimonies from several survivors in this study, from the same institution and during the same time period, soundly contradict this),

people were there because they were forced to be there, living a compulsory segregation. The institutional model disallowed viewing people with disabilities as anything other than a problem population which needs addressing through a highly regimented and medicalized model of care. Finally, such a perspective ignores the reality that the continuation of institutions in Ontario meant a fundamentally uneven distribution of resources. That families who had chosen to keep their child at home did not have easy access to pools or kinesiology could have been a reminder to people within the system that rather than that being a reason to keep institutions open, it was time to devote the moneys historically attached to institutions to bolster what was available in the community. In light of these reflections, it is not surprising that deinstitutionalization was met with caution and trepidation by former staff interviewed for this study.

Fear: “Most people didn’t want it”

In general, participants referred to a pervasive climate of fear surrounding deinstitutionalization. Participants suggested that members of each of the concerned parties—parents and families, staff, and the residents themselves—were opposed to institutional closure. From the perspective of staff, families were frightened of the prospect of a new and unknown situation for their child and themselves after several decades of a government-directed and seemingly secure arrangement. Joe stated:

Most didn’t want it [deinstitutionalization]. Most parents did not want their child or their sibling to move....I think they were afraid of the unknown.

Rory added:

They didn’t know what was going to happen. They were quite happy with the care they were receiving, and they were

saying—*Why are you doing this?*—They would fight with us and say—well, I shouldn't say fight—they would disagree with us and say—*You know, they have their own community here, and their community is HRC. What's wrong with that?*

He went on to describe the extent of emotion that some families expressed once they learned that the institution was going to close:

People were quite upset... we had to call each family member and tell them...So, there was quite a number of families who were very much opposed to the closure. And they were called the Huronia Helpers, which is the parent organization. They fought the closure quite vigorously. There was a court case out of Smiths Falls, and they fought to have the facility stay open.

He described the sense of betrayal that many families felt:

For the past twenty-five, thirty, forty years, the government took care of their family member. All of a sudden they were worried that the government wasn't going to do that anymore. So, there was a lot of angst and anxiety in a number of cases. I had family members, I've had them cry, I've had them yell, I've had them swear at me. I had one lady put a curse on me because we were closing the facility.

Rory noted that families' opposition to closure created difficult situations for the staff responsible for residents' community placements. Staff were faced with complicated

negotiations with families who believed that if they remained firm in their commitment to institutional care, that the government would relent and allow institutions to remain open:

Then the challenge became—Okay, now we have to work with these families very, very closely, because we need their consent. And we want this to work. And what I explained to all of the employees at the time, and the families, was—*You need to understand, we're going to make this work because it has to, because there's no turning back. We're closing all of the remaining facilities.* In prior decades, if a resident left the facility and it really did not work, they could come back. There was no coming back this time. We had to make it work.

Rory described his attempts to explain the non-negotiable movement towards closure to families and staff who were opposed:

I used to say to them—*The train's leaving the station. You can either be on it, or you can be behind it. But it's leaving...* I remember having discussions with family members; I was always pretty upfront and honest with them and I said—*You have to understand. The doors are closing. I can't make it any clearer for you. We both have to work together.*

As some participants noted, families who were open to the idea of community living had already agreed to have their child move out of the institution by the time the last wave of deinstitutionalization was in process. Some families, however, remained steadfast in their

commitment to institutional care, and believed that a ‘sit-in’ response would force the government’s hand.

I can think of one sister of one of the residents. She was totally outraged that this was happening, and they just dug in their heels and they held out to the last minute, which was unfortunate, because they [might have] had the choice of maybe a few homes instead of just the one that was left.

They were mistaken, of course, as all government-run facilities closed on March 31st, 2009, and as one of the participants noted, “the last resident moved March 30th”.

For many families, their opposition to deinstitutionalization was connected to a concern that they were being implicated for a decision now considered badly-informed and misguided, as over the decades, public discourse had shifted to one which advocated for community living for people with intellectual disabilities.

This is the announcement from the government—*the community is the way*—I had families say to me—*Now, just a minute. Are you telling me I made a mistake thirty-seven years ago? Or forty years ago?*

Families were being forced to confront their commitment to the ideology that had informed their decision to institutionalize decades earlier. They had done the right thing, or so they had thought, and now their decision was being challenged by the very people they had trusted in their decision-making about their child.

For forty, fifty years, the government cared for their child.
So, when the government came back forty years later and

said—*The community is the way to go*—they went—*Oh my God, if the government says it, it's got to be true. What did we do wrong?*—So, they really put a lot of faith in what the government told them, because the government provided care for all those years.

These statements are indicative of the power of discourse in regards to the decisions that families were forced to make concerning their children, as well as the influence discourse had in parents' re-evaluation of their own actions many years later. While parents might have felt secure in the knowledge that they had “done the right thing” in placing their child in the institution in the 1960s, this security was deeply shaken as public opinion and government policy began to lean towards models of inclusion and community acceptance. As statements from staff and also from some of the siblings who participated in this project have indicated, the public challenge to parents' original commitment to institutionalization, while stirring some parents on to a new understanding of what might be possible for their children, was threatening to others and facilitated an intense defensiveness. As public debate emerged regarding preferable modes of care, parents were forced to reconcile long-held perspectives of intellectual disability with suggestions that their understandings had been misguided and were deeply dependent on socially-constructed interpretations. This is illustrative of the historically fluctuating nature of understandings of disability, one of the fundamental findings from this research. People who had been relegated to institutions in the post-war period were no different from those the government was now indicating would be better served in the community. Parents who had chosen to institutionalize, therefore, were left to grapple with interpretations of their son or daughter now

considered erroneous, and were being challenged to cognitively reframe their understandings of disability and ability.

Further, participants suggested that some families were uncomfortable with the idea of living in close proximity to a family member with an intellectual disability after several decades of physical and emotional space. They were concerned that community placement would mean an acknowledgement of the existence of disability in their family, and might involve more active participation in their care than they were comfortable with. Joe noted:

I'll be honest, some people who were very opposed to the closure and who had never been very much involved with their family member were pretty adamant about—*I don't want him living too close to me*—unfortunately, they felt, if something happened to the community agency they were going to, because they knew nothing about funding, so if something happened, they were worried that they would be on the hook for care, and the person would be sent to live with them.

Institutional closure therefore re-ignited families' original fears of a shameful connection with intellectual disability, and with the trepidation that they would be left with the responsibility of caring for someone, a prospect they believed they had safely buried when they had chosen to institutionalize.

Staff who participated in this project also referred to a fear of institutional closure from residents themselves. Referring to those who had lived behind institutional walls for most of their lives, staff stated that they believed residents' fear included moving to an environment to

which they had had almost no exposure and to which they had no connection. After decades of living in one place, with a predictable if restrictive routine, concerns about moving to a new situation with unfamiliar people is understandable. Staff suggested that their role in these situations was to act as ‘advocates’ on behalf of the clients, including taking a stand against the inevitable closure of the institution. Wanda described this process with one resident with whom she had worked. In this excerpt, we are party to her interpretation of the government’s stance on deinstitutionalization, as well as her perceived role in the ‘face-off’.

There was a tension... we felt so strongly that we had to really be out there advocating for the clients. And it wasn’t easy, because there was a shift where it became that the focus, the heavy-duty focus, was on deinstitutionalization—*Get ‘em out! Let’s get ‘em out! Let’s get ‘em out!...I’ll give you an example. One of my best friends was a client there... we became very good friends, and they wanted Paul to move out. Paul’s a very capable guy and everything, but he didn’t want to move out. He lived where he lived. He had a very close relationship with staff. He had status; he had status there. Everybody looked up to big Paul.... Big strapping guy. But boy oh boy they wanted him out. He didn’t want to go...but the government had decided deinstitutionalization [was] happening. So, and I don’t know whether it was real or not, but he made them (laughs)—smart guy—he made them sign a contract. He said—If I don’t like it, I want to come back. I*

*want you to give me; I want it on paper that I have a way to
come back if I'm not happy.* Whether or not they would have
honoured that, I don't know.

What is striking from this excerpt is not that a resident expressed anxiety about a potential change in living arrangements, nor that he wrote a letter in defense of what he felt was best for himself, but that Wanda felt that her role as 'advocate' included assuming an oppositional stance against the government—*boy oh boy they wanted him out*—and agitating for the institution to remain open. It was difficult for me, at this juncture in our interview, to not point out that indeed, the government 'wanted' *everyone* out, and that his moving was part of a much bigger process which would ultimately alter the entire landscape of care for people with intellectual disabilities in the province. Moreover, this excerpt illustrates a lost opportunity. Rather than using deinstitutionalization as an opportunity to work with residents to re-imagine a new life and to ensure proper supports were established in the community, Wanda's perspective suggests that their energies were better used fighting a decision which they felt was potentially harmful to residents, but which by this point, was irrevocable. It is important to note, however, that this perspective was offered by a 'front-line' staff person, someone who ultimately had very little control over where and how residents moved out of the institution. In this situation of extreme change, one in which her own position and authority were being undermined and would eventually be eradicated, Wanda's understanding of 'advocate' to mean maintaining the status quo, is appreciable. As discussed in an earlier section, this is a telling example of the insular nature of institutions and the impact that a closed system can have on the impressions of those working within it. While Wanda's concern for this particular resident is evident, it is clear that she is not able, or not willing, to position herself outside of his immediate concerns and

contextualize the movement out of institutions within a framework that would ultimately provide more just and inclusive living arrangements for all people with intellectual disabilities in the province.

Last, participants referred to the fear of institutional closure from their own cohort. Staff noted the ongoing awareness within institutional employees of the ever-present ‘twenty-five year closure plan’ which had been instituted in 1987. Thus, anyone employed at one of the large institutions during that time period worked under the imminent threat of institutional closure, such that “your job was always in jeopardy”. All of the participants noted a pervasive anxiety about the potential loss of work should the institution close its doors. This was exacerbated in 2004, when, in Rory’s words,

Bang! September of 2004, the announcement came—*We’re closing by March 31st, 2009*—which was three years sooner than the twenty-five year plan called for, because it was supposed to be 2012.

Most notably, staff were upset that the government had not honoured what they had understood to be a life-long commitment to stable employment. Sarah explained:

We knew from the government that they were downsizing, and of course there was all that fear, you know, what was going to happen to us as a staff... a lot of them were younger staff that didn’t have as many years, and they were maybe in their forties or whatever, and they were like—*What am I going to do? Nobody’s going to hire me*—Staff-wise, there was great fear.

Rory referred to a sense of betrayal that staff felt from the government:

People were shocked, upset, angry, because for a lot of people, it meant the end of their career... When they signed on, rightly or wrongly, felt they had a career for life.

Participant concerns about the impact of deinstitutionalization on residents and families, therefore, must be examined within the context of their own fears about the impending loss of employment, loss of status, and loss of security. It is difficult to differentiate between participants' varying motivations to oppose institutional closure, as their own articulated concerns for the residents appear deeply interwoven with disquiet about their own future.

However, staff concerns, even if self-centred, bring a cynical perspective that is not unhelpful when assessing the impetus behind the government's decision to impose a policy of deinstitutionalization. All of the staff participants were keenly aware that institutional closure had as much to do with saving money as it did with implementing a new model of living for people with intellectual disabilities. As Joe noted,

I think everything came down to money and taking away the government's responsibility....government does not want to have, they don't want to be front-line... They're removing themselves all over the place. It's probably money... it's gotta be money.

Rory spoke further of the reorganization of services using a business model framework. He agreed that deinstitutionalization was "all about money", but he added that it was a shift in "the way we did business at the facility". He used the metaphor of a spreadsheet to describe the government's shift in priorities:

There's a fixed pot of money, so as they're developing resources in the community, they have to get the money from somewhere. It would make economic sense to take, as residents left the facility, you'd reduce the allocation to the facility, and re-distribute that money into the community.

While Rory seemed to have a sound understanding of how these shifts in funding would occur and appeared quite comfortable discussing care for people with disabilities using a financial framework, other participants were somewhat dismayed that the government would discuss such matters from an economic perspective. Wanda relayed that she had been surprised and disappointed to learn, through an overheard conversation, that government officials determined how much it costs to maintain a facility by estimating the number of dollars needed per resident. While her concern that the human worth of people in the institution not be relegated simply to dollars and cents is admirable, there is an inherent irony here. She was an active participant in a system that never attempted to be anything other than a huge, bureaucratic undertaking, yet seemed surprised to learn that one of the principal impetuses behind changes in policy had to do with money.

The preceding paragraphs give an indication of the complexity of emotional and administrative responses to the spectre of deinstitutionalization as it began to be implemented in earnest at the beginning of the twenty-first century. Complicated by people's faith in a system whose benefits and longevity had been assured them, by people's emotional ties to institutional residents, and by fears of vast change, parents and caregivers alike seemed to reel with discomfort at the prospect. And while staff indicated that they felt some residents were duly concerned, it is also possible that many people living in institutions, caught in the middle of this

ambivalent mix of emotions, felt themselves pulled in various directions throughout. The survivors who participated in this study, however, were absolutely unambiguous in their assessment that deinstitutionalization has been the best thing that has happened to them, and that under no circumstances do they desire a return to institutional care.

To conclude this chapter, I turn to a brief reflection on remaining comments from participants that, while not directly related to the theme of this dissertation, illuminate some of the paradoxes of institutionalization and support some of the contradictions outlined above.

Concluding observations

It is important to acknowledge the esteem with which all of the staff participants in this study held their roles within the institution, as well as the facility itself. They all reported that working at HRC was the “best job I ever had”. Wanda stated, “It’s one of the best things that ever happened in my life. It really, really was (*tearful*). And I wouldn’t have missed it for the world”. Joe stated “it was a good place. If they hadn’t closed it, I would still be there”. This sentiment was repeated by all of the participants. Clearly, for many staff, working at HRC was a positive experience, full of community, companionship, fulfilment, and job security. This presented a dilemma to me, as researcher. How, as observer and listener, does one reconcile this portrait of a loving and vibrant community with accounts from survivors that paint a vastly different picture?

When asked about stories of abuse that have emerged since the institutions closed in 2009, all of the staff acknowledged that, yes, they do believe that mistreatment happened within institutional walls at some points in their history. And they did acknowledge that the military-like atmosphere with which institutions had been imbued for so much of their history, including

the hiring of hundreds of returning veterans after the Second World War, had contributed to an atmosphere of enforced regimentation and rough discipline. As Rory noted,

They were a paramilitary organization. They were used to being told for five years, or however long they were in the navy or the army—*You will; you must; yes, sir; no, sir...* so that's the behaviour they brought with them.

Indeed, Rory and Wendy referred briefly to their encounters with other employees who had been overly rough with residents and had been reprimanded accordingly. Wanda stated, "I knew there were people there who shouldn't work there", suggesting that they were aware of staff whose behaviour towards residents was questionable.

However, staff clearly stated that occurrences of abuse were not a part of their direct experience. Joe stated:

Most people had a really good attitude. Really good. I mean, they were in the right field. I never saw anybody abuse anybody. I'm not saying it didn't happen, I don't know, but not on my watch, not that I ever saw.

Further, as Wanda jokingly observed in reference to a ubiquitous sense of condemnation from the broader community towards people who had worked at HRC "you're blackened and damned because of the actions of a few". However, it is these "actions of a few" that are the crux of survivors' accounts of horrific mistreatment. Despite staff claims that they neither participated in nor witnessed the mistreatment of residents at HRC, survivors' accounts assert that it existed and that, in the words of one of the survivors, "it wrecked me sadly". These discrepancies raise questions regarding the truthfulness of staff comments, their understandings of what constitutes

abuse, and reinforces the importance of public forums within which survivors' assertions can be safely articulated.

Finally, as researcher, I note that the assemblage of such vastly different interpretations of experiences within the same location at the same historical moment offers a puzzling array of "contextualized particularities" (Mabry, 2002, p. 142). Indeed, throughout the research, it was difficult to sustain the belief I was listening to narratives about the same phenomena, so divergent were the interpretations of institutions and their impact on the lives of people with intellectual disabilities and their families. While this presents challenges in the progression through these narratives to a more cohesive analysis and summary, these differences strongly suggest that large interpretative and constructive mechanisms are at play in many peoples' understandings and interpretations of institutionalization. Before embarking on further analysis however, I turn to the last group of findings in this project, those of the key informants.

Chapter Eleven: Findings, key informants

Introduction

This chapter discusses findings from interviews conducted with four key informants. For our purposes here, key informants are people who have significant personal or professional experience with the topic at hand, yet have not experienced institutionalization themselves or through a family member. Key informants offer reliable insight to prominent issues and trends relevant to the focus of the research. The key informant group for this research consisted of one man and three women, all of whom had extensive involvement with people with intellectual disabilities who experienced institutionalization and deinstitutionalization, with their families, and with the agencies who were involved in these processes. Two of the key informants, Walter and Barbara, have been involved in various aspects of advocacy work for several decades; another, Natalie had direct experience with one of the waves of deinstitutionalization which occurred in the late 1990s. Although the sample used for this study is small, their combined longevity in the movement provides an objective and retrospective assessment of shifts in ideology, definitions, and policy that have shaped the history and outcome of the institutionalization of people with intellectual disabilities in Ontario.

Interviews with key informants provided observations in two principal areas of concern: first, they provided reflections on the history and function of institutions, including observations of social understandings of institutions and the oppressive practices embedded within them; and second, they offered observations of families' responses to having a child with a disability, including familial decisions regarding institutionalization and the impact of these decisions. Before embarking on a discussion of these two areas, however, two other observations should be noted.

First, the key informant group demonstrated a distinct bias in support of community living for people with intellectual disabilities. The key informants who participated in this research were firmly in favour of deinstitutionalization and characterized themselves as advocates working on behalf of people with intellectual disabilities. The principal thrust of their observations was in support of the closure of institutions and the establishment of more just and inclusive environments for people with disabilities living in the community. This is not unexpected, as current socio-political understandings of disability are generally, at least in word, supportive of models of acceptance and inclusion in the broader community. Those who currently have a strong presence in forums of concern for people with intellectual disabilities are those who align themselves with advocacy and inclusion, and are also those who were more forthcoming in requests to speak with me. As support for segregation and institutionalization has faded from the public arena (Simmons, 1982), it is no longer favourable in either public opinion or in political spheres to advocate on behalf of non-inclusion, and those who support these options tend to occupy ‘fringe’ positions in the care of people with intellectual disabilities¹.

Second, some of the observations made by key informants overlapped with those made by other groups in this project. These thematic connections and repetitions suggest that specific points of reference in regards to people with intellectual disabilities are shared between different eras and different groups of observers. Notable, however, are the varying interpretations which revolve around these fixed points of concern. Despite common points of reference, different parties frequently invoked variant understandings, dependent on their position in relation to people with disabilities, as well as their specific historical and social location. This is not surprising when one considers the vastly divergent social positions occupied by different participants in this study. As feminist epistemology theorists such as Harding (1993) have

indicated, research which crosses group boundaries struggles constantly to reconcile divergent “socially situated knowledges” (Wilson & Beresford, 2000, p. 557) and that it is vital to be cognizant of the “situatedness within the structures and standards” (ibid) of the bureaucratized institutional system. In light of these theoretical observations, key informants provided a distinctly removed perspective to their analyses, bringing a broader perspective to some of the comments made by other groups, and encouraging critical analysis.

Thematic overlap: examples

For example, both key informants and former staff noted that some of the principal forces behind both institutionalization and deinstitutionalization in the latter half of the twentieth century were funding decisions made by the provincial government. Both these groups identified that these phenomena were at least partially driven by government decisions concerning where and how moneys earmarked for people with disabilities would be spent. As some of the participants in this study have already indicated, the momentum behind deinstitutionalization included decisions by the government to save money and to remove itself from “the business of direct care”, a move which enhanced public perception of the government’s shift away from increasingly outdated notions of institutions as segregated facilities to protect the public, and towards viewing the government as a service provider to people with disabilities (McLaren, 1990; Simmons, 1982). Further, key informants and some, not all, of the staff noted that deinstitutionalization was a necessary step in the re-distribution of resources, such that all people with intellectual disabilities might have equal access to financial support and services. As Natalie observed:

[Families] were looking for help and there was no money,
because all the money was stuck in the institutions... people

living in institutions were getting thousands more dollars of support versus the people who were in the community...I think it was—*We've got to even this out. We have to serve these people who now, their parents are elderly and they can't stay at home anymore and they can't count on always having the support of family. And we can only do that if we even [out] the, if we spread the money around, and we'll be able to do that if we close down the institutions.*

However, it is notable that staff who recognized the fundamental inequity of resource distribution were not 'front line' staff, but were those who held administrative roles which allowed a broader perspective on the functioning of institutions within the larger context of the community. As discussed in the previous chapter, staff whose roles were principally defined by direct care with residents occupied one of the lowest positions in the highly bureaucratized staff hierarchy (Goffman, 1961), and were generally not exposed to discourse which might have encouraged a more expansive understanding of how institutions fit into the broader picture of services for people with disabilities. Accordingly, their views were limited to the impact of broader decisions on their immediate situations, and they tended to view issues such as funding 'cuts' as direct hits from the government towards institutions and the people who lived and worked there. Thus, although the common point of reference here is government funding for institutions, within the institutional hierarchy, those who demonstrated the broadest understanding were those in positions of authority, suggesting a Foucauldian power/ knowledge dyad at work (Simons, 2004b). Indeed, those whose work remained embedded in the day-to-day care of residents were not party to a more complex or comprehensive perspective. They were

more likely to defend the current functioning of the institution, and to view prospective changes as an indication of the end of a specific era, rather than as new possibilities for people with disabilities.

Moreover, key informants recognized, in a way that was not brought forward by staff, that the long holding of moneys within institutions had had a direct impact on families' decisions to institutionalize. That is, many families had placed their child according to where the 'dollars' were. As Walter noted:

I think we all tend to be very influenced in the directions of our lives by where the dollars are, don't we? And I think the dollars were in the facilities. The dollars were not in the community, for the most part... You know, you can imagine families saying—*If I get a pittance from the government, will it be worth accepting it because it will have with it so many constraints, and hoops that have to be jumped through, and accountability that will be imposed upon us when we're exhausted already from providing parental care?* ... Public funds were allocated other than on the basis of need, and on a per person basis, the allocation was primarily in favour of institutionalization....[People in the community] were getting either nothing or very little to be with their families.

Thus, key informants moved the deinstitutionalization debate beyond 'cost-cutting'. They recognized the complexity of funding arrangements and how they fit into long-standing historical arrangements between the province and its population, as segregationist as those

arrangements were (Park & Radford, 1999; Radford & Park, 1993a), and recognized the impact of funding decisions on familial decisions about their children.

Another thematic overlap concerns the general societal discomfort about deinstitutionalization and related factors. This theme was reiterated frequently from several sources in this research, suggesting a ubiquitous anxiety about the closure of institutions and the movement of people with intellectual disabilities back into the community. In particular, key informants' observations that there was widespread fear about the closure of institutions matched those from former staff and from siblings' observations of their parents. As with other thematically similar areas, varying interpretations of this fear emerged. Siblings, for example, noted that they felt their parents were deeply invested in their decision to institutionalize, and thus their anxiety was not only about imminent changes for their son or daughter, but was also rooted in a complex, psychically-rooted self-protectiveness (Marks, 1999). Further, as discussed in Chapter Ten, former staff expressed their trepidation about the closure of institutions as a concern about residents and the losses they would inevitably incur, as well as a fear for their own future. Key informants brought the perspective that anxiety about institutional closure existed in several different groups of people and was expressed in various ways, depending on its source and manifestation. In particular, key informants noted that for families who had institutionalized a child, deinstitutionalization removed the relief they had secured when they, according to Walter, had "placed their child in a safe, protective environment where their physical needs would be guaranteed by the government". What had once been a surety was now open to the chaos of uncertainty, a daunting prospect for parents who, decades earlier, had assumed that they had made a decision for life. Parents feared not only the possibility that they might be asked to provide direct care to their son or daughter, but also the cognitive and emotional re-visiting of

their former decision, one that had already proven taxing. As Natalie observed, many parents did not relish the prospect of deinstitutionalization:

It was too foreign to them. [They were] not comfortable imagining their family member interacting in the wider community.

Moreover, participants from several groups noted that some families did not want their deinstitutionalized child to be located close to them once they had moved to the community. This lends credibility to the notion that many families were uneasy about their family member with a disability and maintained some element of shame (Maybee, 2011). At this point in the re-telling of the family history, however, it is difficult to determine whether those families continued to struggle with the disgrace of having a family member with a disability, or whether their feelings were about the humiliation of having made the decision to institutionalize in the first place. In either case, several parties in this research observed the phenomenon of distancing by family members, despite active efforts from advocates to educate the public about the rightful place of people with disabilities in the community, and the need to build active support networks.

One final example of overlap between different groups of participants concerns the notion that determination and persistence leads to social change, even though this often means stepping beyond the boundaries of what is considered acceptable social behaviour. Here, the most notable similarities were between key informants and some of the parents, in particular those who had decided not to institutionalize their child. These were the people who fought against the dictates of a normative system which refused to imagine possibilities of inclusion for children with intellectual disabilities, a system which moved glacially to implement changes that might shift policy towards this end. For example, Barbara, whose involvement in the movement

began when she volunteered to sit on the board of her local association, spoke of her initial impression of the opinions that others, including parents, held about children with intellectual disabilities:

I was thinking—*This is terrible. It's as though these are not people that we're dealing with.* And I thought—*Well, I've got to find out more about this.*

Barbara described her immediate assessment that there were few options other than institutionalization for families with children with disabilities in the 1960s. In an identical fashion to one of the mothers who kept her child at home, this woman began establishing nursery schools for mothers and children with the principal goal of preventing children from being sent to an institution. Barbara's words--

and that's what happened...nobody was getting one penny of pay, and that didn't matter... The word was getting out... and I kept going

--echo the words we heard in Chapter Nine from Kip, who spoke of her determination to secure government support for her nursery school:

I did it, and it worked... I kept always thinking, the more kids I would see, the more I'd say—Yes, I was right. I'm on the right track. Go for it.

These two women demonstrate that despite differences in experience, and working from different social locations—one as a mother of a child with a disability, one not—change can be instigated through persistence and determination, even if actions are at first viewed as unwelcome interruptions in highly regimented systems of government-sanctioned care

(Manning, 2011, Panitch, 2008). Notably, Barbara spoke in particular about her role as an advocate who could take tremendous risks on behalf of parents of children with disabilities for precisely the reason that administrators could not retaliate through her child:

I was never afraid because I never had a child with a disability. I knew they couldn't get at me through my child. I was safe.

As sad as this assessment is, that parents of children with disabilities might not have acted on behalf of their children for fear of upsetting the authorities and thus endangering their child, it demonstrates Barbara's commitment and willingness to rebuke authorities on their behalf. In an example of brilliant imagination and courage, she recalled taking parents up to the Ontario Hospital School in Orillia when unscheduled visits were not allowed, and distracting security guards by spilling a bushel of apples in the doorway so that mothers could run past and up to the wards to see their children. She reported that as a result of her actions, she was not very well liked by administrators and staff alike, but

I didn't care... they were scared of me (*laughs*). It took me a good number of years to get to walk in and out of there without staff being nervous.

Barbara, besides making a significant contribution to this project through observations which span several decades, also demonstrated the level of commitment that many advocates have shown, with or without a family member with a disability. Without any familial obligation of her own, she saw the need for a strong voice and radical action in order to push the boundaries of what was considered acceptable for people with intellectual disabilities, and she has maintained that role ever since. Indeed, it is striking that three of the four key informants who participated in

this project, while acting as steadfast advocates of people with intellectual disabilities and their families over several decades, do not have the immediate experience of having a family member with a disability, but have felt compelled to act on their behalf via principles of inclusion and justice.

The examples noted above—funding as a decision-maker; anxiety regarding deinstitutionalization; and persistence in the face of resistance—indicate some of the common points of concern between divergent groups within this project. As we have seen, however, shared points of reference are frequently orbited by divergent and sometimes irreconcilable interpretations, and key informants' insights contribute to a more comprehensive analysis.

Key Informant contributions: Institutional observations

Key informants provided important contextual information which contributes to our understanding of the history and function of institutions during the time period with which this study is concerned. Again, their somewhat removed status as observers has allowed a perspective not always achieved when intimately involved in the day-to-day intricacies of daily life, as with some of the other participant groups in this study. Key informants provided a wealth of insight in this area, and while it is impossible to attend to all of their observations, I will address three in turn.

First, participants referred to the tremendous influence that institutions held within medical and social service circles in Ontario in the latter half of the twentieth century. Institutions were mainstays in the political landscape surrounding people with disabilities, and remained so until deinstitutionalization began to be implemented with vigour in the 1980s and 1990s. As Terri, as well as Simmons (1982) noted, even deinstitutionalization was ironically dependent on the perpetuation of institutions, as the government's original attempts at

deinstitutionalization included the refurbishing of several old military bases in order to gradually ‘ease’ former Schedule One residents into a slightly smaller, more vocationally-oriented setting which, in essence, meant no real change in the conditions under which people were living. Indeed, although Williston (1971) made recommendations as early as 1971 to begin institutional closure, it took more than thirty-five years for this proposal to be fully realized. Accordingly, participants here noted that families in the postwar decades were under tremendous pressure to place their family member in an institution. In regards to who might have exerted pressure on the family, Walter stated,

Anybody with a status in the community, that commanded respect—clergy, probably, probably teachers, because you know –*Sorry, your boy can’t come to school, because he’s not educable. He could do better in an institution.*

Indeed, participants spoke of the resistance to deinstitutionalization from many corners, and pointed out that large-scale, government-run institutions continue to function in four Canadian provinces.

Thus, Walter noted that as the twentieth century drew to an end, the principal work of most advocates became institutional closure. He stated that when he came on board with advocacy work in the late 1970s,

the spectre of institutionalization hung over us... we had certainly come out of that period, I think maybe just a couple of years earlier, [during which] some people were saying—*We’ve got to fix these places up*—And then people were

whispering in my ear—*No, no, no, no. We have to tear these places down.*

Work on behalf of people with intellectual disabilities had become advocacy work, “and advocacy pointed in the direction of closure”. Indeed, it had become “unthinkable” by the late 1970s for Associations for Community Living to pass any resolutions which called for re-investment in institutional upkeep. Thus, from the key informants’ perspective, real advocacy, working on behalf of people with intellectual disabilities, meant focusing on institutional closure, and did not allow for conciliatory measures including improvements in their condition.

Second, all of the key informants identified the embedded nature of abuse within the institutional system. Beyond the blatant, horrific accounts of mistreatment that survivors of institutionalization have begun to share in the years since institutional closure ², key informants, all of whom visited an institution at some point, observed what they interpreted as abusive situations, despite their seeming innocuousness. For example, Walter referred to the schooling that took place within the Ontario Hospital ‘Schools’. He recalled a classroom that he observed while on a tour of a facility, in which several youth were being taught about synonyms, antonyms, and homonyms:

I didn’t go much further than saying—*If these people can learn the meaning of synonyms, antonyms, and homonyms, well, do they need to be in an institution?* And of course what I should have been saying is—*Does anybody need to be in an institution?* But that was one of the things that really constituted an abuse, that they were being forced to learn something that they should have had an opportunity to

learn—if it was important for them to learn it in the first place—without being institutionalized.

Recognizing that school within institutional walls fundamentally constitutes an abuse is a direct contradiction to the perspective of former staff, who deemed the existence of extensive facilities within the institution as one of its principal assets and one of the reasons why institutions should remain open, as residents' needs are then conveniently met in their entirety.

Natalie also identified what she deemed abusive situations which she observed while visiting. From her perspective, the restraint that institutions imposed on residents through medication and other means “crushed people’s spirits”.

I noticed there were some very large men with disabilities who were very peaceful, calm-looking, but a bit zoned-out looking too...there was not one ounce of violence in these people. I thought “*Who* crushed their spirit? Who stepped on them that they have no uumph?” There was no uumph... no resistance... everyone was *well* under control, was very controlled.

She went on to describe a recreational outing at the facility:

So they said—*We’re going to have a beach day; why don’t you come? Everybody’s going to the beach*—So, I was like—*Wow, I’ve never seen the lake*—They’re on the lake, it’s this beautiful property. So, I went for the beach day. *I was mortified*... It was treed and grassy, like a park. There was no sand, and I couldn’t see the water. Nobody could see the

water. So people were just... people were grouped according to cottage...the whole Huronia was there that day, but all grouped. And the guys who were ‘violent’ had on jumpsuits; *they were tied at the back...* they just had to stay in their little area...they weren’t eating when I was there...they were just pacing around, and the staff were just hanging around. And that was the beach day. It was really awful .

Natalie felt a profound disjuncture between her observation of this outing, a ‘special’ day in the lives of the residents, and the interpretation offered by staff:

There were hundreds of people in that situation; there would have been, gosh, maybe sixty staff; there were hundreds of people with disabilities, it was just normal. That was a beach outing for them. And it was so not normal, and so not right in my mind.

The disconnect between Natalie’s assessment of the ‘offerings’ of the facility, which she interpreted as blatant examples of the oppression that institutional residents had to endure while living there, and the interpretation from staff that these were the features that made it a wonderful home, was further exacerbated when the staff provided a tour and pointed out all the amenities it had to offer:

The hairdressers, the morgue... They showed me with pride, all the things they had—*We have everything*—they would say.

These examples, when viewed through the advocacy lens to which key informants are committed, indicate the ironic perspective with which institutional life is imbued (Goffman,

1961). What the staff deemed brilliant amenities which enriched residents' lives, key informants defined as abusive by the very fact that people were being denied access to them through regular channels. Moreover, residents' access to the 'positive' features of institutional life—the hairdresser, the pool, the exercise—were conditional on their surrendering a great deal of their lives, including choosing where they might live, regular connections with family, and the freedom to experience life in the community. Key informants were able to deconstruct and invert the staging of services that a positive presentation of the institution was dependent upon, and recognized it as an example of the oppressive limitations that people with intellectual disabilities were forced to live with so long as they were situated within institutional walls.

Thus, key informants make a significant contribution here, for they indicate the extent to which discursive constructions can create meanings that euphemize existing abuses and justify the limits of an institutional system. While this might not have been an intentional rhetorical strategy on the part of staff (Stapleton & Wilson, 2008), the misrecognition of injustices might be attributed to the “situatedness” (Wilson & Beresford, 2000, p. 558) of institutional workers in an oppressive system, wherein “polarized representations” (Jacob, 2014, p. 46) encourage limited understandings of residents, staff, and indeed, the ‘services’ offered. As Goffman (1961) has indicated, the stereotypes inherent to institutionalized systems, including the unquestioned acceptance of amenities as life-giving arrangements, shore up the functioning of the institution as a whole. These examples point to the conviction embraced by all of the key informants that institutionalization was not an option, regardless of the quality of the services the system claimed it offered. As Barbara stated, “everything led me to say ‘no institutions’ no matter how good the people are”.

Third, key informants demonstrated knowledge about the steps needed to move away from an entrenched institutional system, and to foster a more robust network of community living. They were well versed in constructive approaches that would eventually lead to institutional closure and the improvement of supports in the community for people with intellectual disabilities. As Walter stated,

a government decision is a better way to go than a judicial decision to force the hands of government. It's more planful and tends to be supported by more community based service development.

Despite feeling pressure as an advocate from some families to go the “litigious route” and sue various institutions for maltreatment and “demand on behalf of institutionalized people that they be liberated and [institutions] be closed”, and despite the government’s notoriously slow pace towards change, Walter felt that in the long run, it was better to secure the shuttering of institutions via legislation and increase the protection for that development through the arms of government.

Moreover, key informants indicated that over the decades, they had been willing to consider the concerns of people with disabilities and their families beyond the immediate, and had maintained a visionary and lengthy perspective on non-institutional possibilities. Even those who had acted as advocates during the height of institutional admissions, including Terri, Walter, and Barbara, had worked under the presumption that eventually, meaningful places for people with disabilities in the community would be realized. They were determined to vision beyond what was immediately available, that is, the pressured recommendation to institutionalize, and imagined other possibilities. While acknowledging that many families had institutionalized their

child in part because of the lack of opportunity to learn from those who had chosen otherwise, key informants were aware that families who had worked to establish a meaningful life for their child outside of the institution did exist. Natalie commented:

Families *had* been successful in the community. So, there were now people grown up in the community, versus people who had grown up in the institution and never the twain shall meet. And the people in the community, the people with disabilities, they had relationships, they were well, and in terms of the needs they might have had for support, they could look exactly like someone who was living at Huronia. And they were fine. They were doing well. Plus, they had the benefit of their family around them, and a neighbourhood, and lots of people in their lives.

Natalie noted that the years of groundbreaking work and perseverance by families who had chosen to keep their children at home had begun to have positive outcomes, not only for their own children, but for all those who eventually ended up living in the community.

I think because... this generation that has been so well integrated into the community and more dignified in the eyes of the wider community, the context is very positive for people with disabilities... the fear has dissipated a lot...there are people who advocate for themselves or just are themselves in the community... and their presence speaks volumes and people notice them... and that's a big change.

This echoes the insights of the two mothers, discussed in Chapter Nine, who did not institutionalize their children and had predicted that their work would eventually prove pivotal in the longer term for people with disabilities living in the community. One of these mothers, Kip, had stated:

You have another role to play. It's not the role you planned for yourself at all, but it's a role that's going to help a lot of other people.

In general, the willingness of key informants to assume a lengthy and critical view of the situation of people with intellectual disabilities provided a depth of perspective not easily gained from those more intimately connected. It is an essential and, some might say, privileged perspective (Kirby & McKenna, 1989), but in the cases of participants here, comes after decades of committed involvement and thoughtful advocacy. All of them were willing to engage with interpretations of disability that had seemed unimaginable when institutionalization was at its peak. They were able to construct alternatives to the hegemonic discourse of intellectual disability as a family tragedy, all the more notable when one considers the era within which some of them began their advocacy work. As Walter stated in response to concerns from institutional staff that deinstitutionalized individuals would lose too much of their lives upon leaving the institution:

I guess all we could say was—Let's believe that Annie can form new relationships. Let's believe that she will do so with more variety and richness than has been the case for fifty years.

Key Informant observations: family situations and responses

Key informants in this study were in the unique position of being able to observe varying familial responses to institutionalization with a more distanced perspective. They were party to narratives that were both supportive of and opposed to institutionalization, allowing them to view all interpretations as reasonable, and to face all parties with understanding, even if fundamentally they might have disagreed with different families' decisions about their children. According to participants, there was a clear distinction between families who had chosen to institutionalize a child, and those who had kept them at home. The first group had "done what they were told", and, from this participant's perspective, remained confident that they had done the right thing. Natalie noted:

Even though they might have only gone once a year, like to the annual review or for the birthday, or... hardly went at all, they still felt integrity in their relationship. And they felt good about what they had done for their family member. I didn't hear them saying regrets.

In contrast, as discussed above, were the families who had resisted the discourse of obedience and had refused to admit their child to an institution. This same participant recalled a conversation between a mother who had kept her child at home in spite of recommendations to do otherwise, and parents who had institutionalized their children and were now, decades later, faced with the prospect of having them live in the community:

She said—I felt like I had nothing to say. These are my peers.

The people who, forty years ago, listened to the doctors and said—*Okay, that's what you think we should do*—And the rest of

us on this side, said—*No, we don't feel right about that, we're going to try and carve out own way and build our own in the community.*

Notable in this excerpt is the mother's own admission that these two groups of parents, despite their lack of shared history and their minimal contact with each other, were, nonetheless, peers, a resource that was rarely utilized in situations that would have had common concerns.

Accordingly, Natalie suggested that these distinct sets of parents rarely came in contact with each other. As the focus of advocacy groups and associations for community living at the time was institutional closure, their work was moved forward by parents in alignment with this thinking, and those who did not want institutions to close were rarely heard from. From Natalie's observations, she felt that animosity existed between the two groups, that

some people [who had institutionalized their child] felt deserving and looked negatively towards those families who had put their child in an institution.

This sentiment was echoed by Elisabeth, one of the mothers interviewed for this study. Having reluctantly placed her son in an institution for one year, she felt that she had been judged accordingly, and that it took sustained effort on her part in the community living movement to re-establish herself as a genuine advocate on behalf of her son.

However, Walter noted a further distinction. He felt that parents who advocated for institutional closure included both those who had never placed their child in an institution, and those who had done so reluctantly. While these parents' goals were identical, their motives originated from different experiences:

[The group who advocated for closing the institutions] included parents who had resisted the pressure to place their child in an institution, and those who had, I think very reluctantly, yielded to that pressure. And both of those groups were, each had their own unique contribution to the argument in favour of deinstitutionalization. And I think there was more emotion among those who had yielded to the pressure than there was among those [who had not]. The ones who opposed institutionalization because they had made a decision against it were naturally more gravitating towards the theory of why it's wrong, than the lived experience of the wrongfulness. So, it's interesting to reflect on that.

He suggests, therefore, that distinctions in and among parents were perhaps more complex than they appeared. Not all of the parents who had institutionalized their child wanted the facilities to remain open; indeed, they based their advocacy work on the direct and debilitating experience of making the decision to institutionalize their child, and acknowledging the harm this had caused. Parents who had chosen not to institutionalize their child drew their assertions, rather, from their conviction that institutionalization was a morally reprehensible act in the first place.

In this context, it is easy to understand how judgement and dissent between groups of parents might have festered. However, Walter recalled:

Over a period of thirty-five years, I have had opportunities to converse with both groups, and of course they came together as an advocacy group. They were essentially the backbone of the

community living movement. So, they weren't at odds with one another; they just had—they came from different perspectives.

From this generous assertion, one can only assume that indeed, if parents really did “come together as an advocacy group”, they must have sorted out some way to reconcile their variant experiences and determine how to work together to achieve a common goal (Panitch, 2008).

Another area in which key informants offered an important perspective concerns the overall understanding that parents had of their institutionalized children. Terri and Natalie noted that the milestones parents used to mark their child's movement through life were framed entirely within the medical model. As there were no other milestones to which the parents were witness—indeed, within the institutional environment, rarely were milestones marked other than those that could be measured, weighed, or achieved through medical procedures—they had no alternate means to understand their child's gradual development from childhood to adulthood. Natalie observed:

[Parents would say]—*this year, they had this test done, and they had this surgery done*—The parents knew all the stuff that was done for them, kind of chronologically; they would have that the way we would have, you know, graduation from kindergarten, those different moments. They had it in the medical [model].

As change was noted through the measurement of the body, parents were generally not party to knowing their children as complex beings. Terri noted that they had limited opportunity to come to know their children in emotional and spiritual terms, nor to understand milestones as something other than the physical changes we encounter as we age.

This bore direct consequences. Participants noted that parents often continued to see their institutionalized children as ‘children’, regardless of age: “he was still their boy, and he wasn’t a ‘bad’ kid to her”. While some literature suggests this is a not-uncommon phenomenon for many parents of children with disabilities (Bailey et al, 2006; Reichman et al, 2008), the physical and emotional distance that institutionalization established within families would have exacerbated parents’ impeded understanding of their child as someone who would grow and change, and who would become capable of making decisions about his or her own future. In this regard, participants noted that some parents saw their child’s dependent status as a guarantee that they would always have legal and decision-making rights over them. Walter described the opposition he encountered as he worked to promote the fundamental rights of people with intellectual disabilities, both within institutions and within the broader community:

I became exposed early on to the issue of institutional wrongs; I also become exposed to all manner of other wrongs, of course. And this particular lawyer... he came to me with a list of offences I had committed, like advocating against parents who wanted their children to be dead...I was acting contrary to their wishes, contrary to their interests, contrary to their rights over their children, by saying that they should be in regular classrooms with other children, all manner of things.

As his observation points out, while institutions were not the only arena in which the rights of persons with disabilities were being blatantly disregarded, they remained part of an entire system of oppression in which people with disabilities were never considered fully capable of living their own lives. He added:

If once our main theme was—get people out of institutions—our main theme now is to support people to make their own decisions, rather than taking away all decision-making authority and excluding them from the process.

Walter's acknowledgement of the changing nature of his role as an advocate leads to our last major area of reflection in this particular area, which concerns the role that key informants have played in the lives of people with intellectual disabilities and their families over the years, and why they remain central in the quest for a just and inclusive society.

Barbara, who saw her role as someone who could help families to avoid institutionalization, said:

If parents were told by a doctor to send their child to an institution, I would come in like a ton of bricks. I would sometimes stay with the family for a couple of days to help out.

She explained that she would sometimes strike a deal with a family in order to try and convince them not to institutionalize their child. In one instance, she asked a family—the father of which had initially said “You’ve no idea what you’re asking of us”—to try and keep their baby at home for ten years. The family kept the baby; Barbara called back ten years later, and of course, by that point, the family could not imagine having their daughter anywhere else.

I quote this example not for its quaint and almost unbelievable simplicity, but because it indicates that the key informants who participated in this project were effective, in part, because they had nothing to lose. They were committed to the closure of institutions and spearheaded instrumental work towards this end. But this commitment was aided by a deep knowledge that no harm would come to them or their families should they do something considered a misstep by the

authorities. While their actions were frequently questioned by administrators, lawyers, and co-workers alike, the participants here have maintained an absolute commitment to advocacy work on behalf of people with intellectual disabilities and their families because they believed in what they were doing and, in their own words, “did not care” what others thought of them.

Accordingly, the key informants who participated in this study also felt some freedom to speak to parents about possibilities not yet imagined for their children. “I did everything I could to help parents know the full personhood of their children”, Barbara noted. She encouraged families to remain committed to their children when they moved from the institution to the community, to “let them have their dreams” in the same way that parents might wish grand things for their non-disabled children.

While this might be construed as a privileged position, and indeed, it is difficult to dream big dreams and gain perspective on longer-term visions for people with intellectual disabilities living in the community while attending to the immediate and pressing needs of one’s family, the key informants in this study have demonstrated the importance of including people who have energy, experience, and critical perspective in movements for social justice.

This chapter concludes the findings section of the dissertation research. Findings from all five of the research groups have been presented and briefly analysed. In order to bring the research to a summative conclusion, the next chapter will bring together the findings from these five chapters into an analytical framework, and will draw appropriate conclusions.

Chapter Twelve: Summative analysis

Introduction

This chapter presents a summative analysis of the findings from this research. The task at hand is to draw together the analyses and insights already derived from reflections from Chapters Seven to Eleven, and to bring them to a common forum of discussion in order to arrive at a cohesive analysis and conclusion. This is a daunting proposition when the multiple research groups, their variant positions and experiences, and their contrasting histories are considered. Accordingly, the first section of this chapter deals with the methodological considerations that must be taken into account when attempting to impart a succinct summary from a broad field of study. In this section, I attend to the postmodern dilemma of addressing multiple experiences while attempting to organize them into a unified whole (Davison, 2006). From there, the chapter moves into the four major areas of discussion which best reflect the principal findings from the research. Each of these areas has emerged in previous chapters; this final discussion provides the location in which principal points of intersection are identified, conclusions are drawn, and their meaning in relation to broader concerns around disability and disability studies are interrogated. The four areas of discussion are as follows. First, I will draw from the research to examine theories of power and governmentality in regards to intellectual disability, in particular how power has been manifested through institutionalization practices. Second, the notion of intellect will be examined, particularly how the construction of intellect has historically contributed to institutionalization, and how fluctuations in public understandings of intellect have resulted in continuously-shifting responses to people considered intellectually ‘inferior’. These first two sections lay the foundation for the third area of reflection which concerns the principal area of investigation in this project, the impact of institutionalization on family relationships and

understandings of disability. And fourth, I attempt to contextualize and incorporate the above analyses within the notion of disability and the field of disability studies itself, indicating future directions to which this research might point.

Methodological considerations

While details of the specific methods employed for this research are discussed in Chapter Six, the following discussion considers the task of drawing together a multiplicity of experiences in order to draw a distilled analysis. Situated as it is in a scholarly era wherein “previously unquestioned epistemological assumptions on which cultural representations rest” (Van Maanen, 1988, p. x) have been challenged by new methodological considerations brought forward by “postmodern, feminist poststructural and postcolonial theories” (Davison, 2006), my analysis attempts to identify underlying themes and patterns in the midst of fractured and variant narratives. At a time when researchers are asked to consider and challenge “hegemon[ies] of imposed unity” (Mabry, 2002, p. 142), this project is marked by the distinct postmodern dilemma of “developing findings in dissensus” (ibid, p. 148). As Lather (1991) noted in her early text devoted to postmodern feminist emancipatory work, this kind of analysis is a response to “the contemporary crisis of representation, the profound uncertainty about what constitutes an adequate depiction of social ‘reality’” (p. 21).

Faced as I am with vastly different interpretations of a common phenomenon grounded in a common time period and location, it is indeed difficult to know how to “adequately represent” what “really” happened within families, and within the ever-shifting dynamic between cultural representations of disability and people labelled as such through political, social, and medical forces. The “uncertainty” to which Lather refers suggests it is difficult to know how to proceed when confronted with such profoundly different interpretations. Mabry (2002) suggests

that researchers “articulate multiple perspectives... [and] direct attention to multiple realities” (p. 152).

However, as committed as I might be to honouring the “multiple realities” laid bare in the narratives of this project, I cannot hide from my earlier assertion, made in the initial pages of this dissertation, regarding my use of an advocacy lens for the duration of the project—that is, the assumption of a viewpoint which takes the historical oppression of people with intellectual disabilities into account. While it is perhaps contestable that my role go beyond anything but provide a comprehensive overview of the findings at hand and a summation of what can be discerned there, it seems that in order to remain faithful to one of my initial objectives—to provide an examination of institutionalization and its impact on the people who lived there and their families, a process which was inherently unjust in its underlying principles—I experienced the felt need to claim allegiance to one position more than another. My stance here is supported by Mabry (2002), who suggests that “responsibility can serve as a citadel in the shifting sands of postmodernism” (p. 152), and that “the bottomless skepticism of extreme postmodernism” (ibid) can be replaced by an “affirmative postmodernism” (ibid). In defense of my position as a researcher who ultimately felt more compassion for certain groups involved in this project than others, and felt committed to ensuring that particular voices—those with historically minimal input in the grander scheme of social discourse—would be given credence, Mabry states:

Girding for responsible action in the light intellectual armour
of hope and values, affirmative postmodernists tend to
believe that, although consensus cannot be expected and
rationales cannot be protected from challenge, some

behaviours are more justifiable than others, some values more worthy, some criteria more appropriate (p. 152).

Thus, I wade forward into the morass of variant narratives, histories, and experiences, aware of the dissent among and between them, and knowing that I position myself with perhaps a more open ear and a kinder heart in front of some than others.

Last, this analysis is embarked upon with an acknowledgement that each step of the analytical process is done as an “act of textual recreation” (Davison, 2006, p. 134). Aware of assumptions of the “descriptive adequacy of language as a transparent representation of the world” (Lather, 1991, p. 107) undergirding much research, and my own impulse to fall prey to that assumption, I acknowledge that at best, I am producing an imperfect representation of lived events (Davison, 2006; Holstein & Gubrium, 2013; Van Maanen, 1988). As Denzin and Lincoln (2013) have repeatedly stated, qualitative research is an “interpretive, material practice that... turns the world into a series of representations” (p. 6), and it is “the researcher who ultimately... creates the text” (Fontana & Frey, 2005, p. 697). Accordingly, as this project’s researcher, I assume responsibility for the acts of interpretation upon which this chapter is based, and acknowledge that one of the principal findings is the existence of a multiplicity of possible interpretations, of which I am constructing only one.

Power, governmentality, and institutionalization

Findings from this research point consistently to the need to acknowledge the interconnectedness between manifestations of power during the time period of concern, and what Tremain (2005) refers to as “the government of disability” (pp. 1-24). While several disability studies scholars have pointed out the importance of recognizing historical “ontological” (Shildrick, 2002, p. 17) and “aesthetic” (Hahn, 1989, p.370) anxieties in response to disability,

(see also Marks, 1999; Thomas, 2002, and Wilton, 1998), this research suggests that attempts to bring some meaning to the phenomenon of institutionalization must include not only discussions concerning the fear of difference and the subsequent need to segregate and make invisible that difference, but to thoroughly interrogate the power structures within which segregation policies were embedded. The findings from this study further suggest that both macro- and micro-analyses of power are appropriate, as this study touches upon both the ‘superimposition’ of political and social forces on those most implicated in institutional processes, and the more subtle interplay of power and decision-making between and among individuals and family members.

Consideration of the influence of macro systems of power, particularly as explicated within a Marxist framework, is helpful in understanding larger political and social forces which contributed to the establishment of segregated institutions and to their continuing presence in the specific time and place with which this project is concerned. In Chapter One, the scholarly body of work which theorizes historical and materialist forces behind the establishment of institutions in general was discussed. While these theorizations will not be reiterated in detail here, it is important to acknowledge that broad analyses of institutionalization, including its underlying economic and political influences, are relevant to understanding the more intimate details of individuals’ direct experiences, such as those encapsulated within this study, despite the apparent theoretical distance between them. In particular, Scull’s predominantly materialist analysis of the “functional requirements of a [rising] market system” (1979, p. 40) which led to the steady “shift to the asylum” (1983, p. 130) in Victorian England, and Rothman’s (1971) theorising regarding the establishment of institutions as a response to a fear of social disorder in post-colonial America, while both addressing historical “meta-narratives” of institutionalization,

point to social conditions that remained relevant to families dealing with decisions concerning institutionalization well into the twentieth century. That is, the market-driven and disciplinary functions of institutions, as iterated by Scull and Rothman respectively, despite arising generations earlier than the time period of this study, remained influential to the families involved. As Simmons (1982) makes explicit, the “administrative economies” (p. 32) of large-scale institutions which both supported and were supported by a growing capitalist economy, allowed institutions to grow and flourish as logical and economically sound methods to deal with people considered too difficult to integrate into mainstream society. Generations after their establishment, institutionalization persisted as the most financially feasible option to many families with a family member with a disability, particularly in light of the fact that within the social welfare parameters existing at the time, there were few other means of support, financial or otherwise (Guest, 1999). Moreover, as Simmons (1982) and Reaume (2006, 2004, 2000) have pointed out, the establishment of exploitative labour practices within institutions further entrenched them as economically viable features of the social welfare system, exacerbating the political inertia around establishing more community-minded alternatives which lasted well into the 1970s.

Beyond economic and materialist considerations, accounts (see, for example, McLaren, 1990; Radford, 1991; Radford & Park, 1993a; Simmons, 1982) of fear-inspired interpretations of intellectual ‘inferiority’ are re-iterative of Rothman’s (1971) assessment of the influence of ubiquitous anxieties of social and moral decay in an era of new social and geographic mobility. While the families in this study were not of the time period to which Rothman refers, the contributions of parents in particular suggest that his theories of the felt need to impose order on an otherwise potentially disruptive and fearful element are appropriate.

The contribution of broader social elements that contributed to families' decisions to institutionalize as outlined above is only one part of the discussion concerning power dynamics, however. Our understanding of the influences that led parents to place a child in an institution is further enhanced by examining the micro-narratives at play within the social fields within which families were operating. It is here that an examination of Foucault's historical excavation of the evolution of "disciplinary subjection" (Barker, 1998, p. 51) are helpful. As Foucault (1977) states:

What was then being formed was a policy of coercions that act upon the body, a calculated manipulation of its elements, its gestures, its behaviour. The human body was entering a machinery of power that explores it, breaks it down and rearranges it. A 'political anatomy', which was also a 'mechanics of power', was being born; it defined how one may have a hold over others' bodies, not only so that they may do as one wishes, but so that they may operate as one wishes, with the techniques, the speed, and the efficiency that one determines. Thus discipline produces subjected and practised bodies, 'docile' bodies (p. 138).

Moreover, the "machinery of power" in which Foucault situates the locus of control in the creation of the disciplined subject is not, he specifies, a "constant, total, massive, non-analytical, unlimited relation of domination, established in the individual will of the master" (ibid, p. 137), but, rather, is an exhibition of the extensive hand of coercion. Thus, in Foucauldian terms, power is "more a question of the direction of conduct than it is a question of confrontation between

adversaries” (Tremain, 2005, p. 8). That is, in order to appreciate power’s influence at the individual and communal level, we need to examine power’s subtle exertion, its “conduct of conduct” (ibid, p. 9), in contrast to the more prevalent “juridico-discursive” interpretation of power as “fundamentally repressive... possessed by a centralized external authority” (ibid).

In the context of our concerns here, Foucault’s theories of the coercive nature of power have theoretical implications on both those who were institutionalized against their will, and on the families who made the decision to place them there. Foucault (1977) suggests that the discipline of the institution “increases the forces of the body (in economic terms of utility) and diminishes these same forces (in political terms of obedience)... and turns [power] into a relation of strict subjection” (p. 138), painting a picture of powerlessness that concurs with those given by institutional survivors who participated in this study. Sadly, however, statements from survivors also indicate that the disciplinary regime experienced in institutions went beyond the notion of coercion, and included instances of explicit harassment and abuse, “confrontations between adversaries” that had frequent opportunity to erupt. Moreover, survivors’ recollections of rebellious behaviour on their part in order to ensure at least minimum standards of living, and indeed, acknowledgement of their existence, trouble Foucault’s notion of the docile body, an interpretation that “underestimates the body’s role as subject, as an agent of self- and social transformation” (Hughes, 2005, p. 80).

In regards to families, however, Foucault’s notion of the “conduct of conduct” is in close alignment. Parents’ decision to institutionalize their child did not fall under the strictures of governance per se—no law *required* families to place a child identified with an intellectual disability in an institution—but, as several of the participants in this study have indicated, coercive mechanisms were at work, particularly through the official channels in which the

authority around institutional placement was invested. Typical of the era, and the behaviour expected of women in particular, families faced with such decisions would have been heavily influenced by ubiquitous notions of doing what one should in order to participate meaningfully in the broader picture of postwar citizenship. As one of the participants stated, “My mother would be very determined to do the right thing, to do what she was, in effect, told to do. Quite strong on ‘ought’”.

Additional findings concerning power have materialized from this research. These findings incorporate both the macro (i.e. structural and systemic) and micro (i.e. individuated) conditions discussed above, and cross the boundaries between different groups of research participants. First, a pattern emerged which indicated that those who felt most acutely, and indeed, who appeared to suffer the most from the negative implications of power dynamics as embedded within institutionalization processes were those who have traditionally occupied marginal positions within society. That is, within the parameters of this study, people identified as having intellectual disabilities and women were more likely to experience harmful repercussions from the singular decision to place a family member in an institution. A site-specific irony thus emerges wherein those who occupied social positions most removed from central locations of power and authority tended to occupy emotional positions most proximal to the negative experience of institutionalization. From a situational perspective, those positioned on the outskirts of power were most firmly embedded in the centre of institutionalization’s negative ramifications. This is, sadly, understandable in regards to people identified as having intellectual disabilities: the furthest removed from circles of power, they suffered enormously at the “dehumanized” (Hubert, 2000, p. 200) heart of the institution. In these instances, Young’s

(1990) interrogation of the relationship between marginalization from centres of power and the felt suffering of individuals is made explicit.

Somewhat unexpectedly, however, was the extent of the suffering expressed by those who could be considered next furthest removed from positions of authority—namely, women and girls. Repeatedly throughout this study, the mothers and sisters of those institutionalized remarked upon the negative repercussions of institutionalization in their own lives. As discussed in the methodology chapter, the small sample size and the unequal gender distribution in both the sibling and parent groups prevents this observation from carrying import within these two groups. Indeed, further research with a more balanced gender distribution, and further excavation of the differences in male and female responses in interview settings, would be required in order to draw conclusions. Nonetheless, the power / suffering dyad as articulated by these particular participants is notable. For example, as indicated in Chapter Eight, many siblings identified the suffering that their mothers experienced after having made the decision to institutionalize their son or daughter, manifested in various ways, including relentless stoicism, regret and sadness, and in some cases, extreme depression which lasted for much of the rest of their adult lives. Further, most of the sisters of institutionalized individuals referred to their own struggles with this piece of their family history. They indicated that their parents' decision to remove their brother or sister from the family home has been a significant marker of their identity and of the role they have carried within the family, and that it has resulted in an ongoing emotional and reconciliatory journey. In contrast, the brothers and fathers interviewed for this particular study did not outwardly express the same depth of emotional anguish. In general, sibling participants spoke of their fathers' distance from both the process and manifestation of the decision to institutionalize, a position encouraged by the male occupation of non-domestic roles outside of

the family home. As one sibling noted, “He was absent. He was very present professionally. And ... absent in the home. He absolutely never spoke about Kevin; he absolutely did not visit him”. Again, as outlined in the sample section of the methodology chapter, this may indicate no more than an unwillingness or discomfort on the part of male participants to share personal experiences with a stranger, an understandable phenomenon particularly in regards to the generation of men interviewed here. Further research is needed to determine if men from families who have experienced institutionalization have indeed coped with this piece of their family’s history with a greater degree of emotional distance than that of their female counterparts, and to explore the nature and depth of their suffering in relation to this phenomenon.

One final observation in regards to the connection between experiences of institutionalization and manifestations of power concerns the internalization of systemic markers of power, or, according to Maybee (2011), processes wherein the “political becomes personal” (pp. 245-259). While Maybee refers to parents’ “compensat[ion] for the devalued bodily capital” (p. 255) of their children with disabilities in this process, I include here the notion that through their participation in institutionalization processes, unwilling or otherwise, the families of institutionalized individuals as well as survivors absorbed the material effects of the power structures and disciplinary organizations at play, such that they experienced these materializations at a deeply personal and embodied level. This was, of course, experienced most profoundly by survivors of institutions, as evidenced in the psychological, emotional, and frequently physical marks that they endured and continue to carry, many years after leaving the institution. While the bureaucratic web and segregation within which institutions were embedded might have obscured the practicalities of their existence in the public arena, survivors who

participated in this study indicated that the personal and material effects of institutionalization were felt every moment they were there, through regimentation, oppressive practices, and abuse. As discussed in Chapter One in regards to the nature and extent of the institution as an embodied phenomenon, former residents indeed bore the insignia of their incarceration, and became what Grosz (1994) refers to as “... site[s] of social, political, cultural, and geographical inscriptions” (p. 23). Moreover, although parents’ points of intersection with the symbols and structures of institutional power seemed to be at the level of practical decision-making and concurrence with predominant discourse, findings from the research suggest that the mechanisms at play were also experienced in a deeply embodied way. Try as they might to contextualize the decision to institutionalize as the only reasonable option to which they were party, parents, particularly mothers, indicated that it was difficult to distance themselves from the emotional and physical impact of placing a child in an institution, and they lived some of the immeasurable consequences of this for the remainder of the lives. Accounts of severe depression, anxiety, regret, and physical ailments as described by some participants suggest that while scholarship has, to date, focussed on the political and social implications of institutionalization, processes such as these that work their way into the very heart of people’s lives carry significant personal consequences. Thus, although parents often presented their decisions as necessary within the circumstances of their lives at that particular moment, something one simply “gets on with”, their accounts suggest a rather more corporeal experience.

Intellect, or categorizations of being

The discussion above examines the nature and direction of power as a component of institutionalization processes and its manifestation in the materiality of people’s lives. Connected here, but requiring further analysis is the notion of ‘intellect’ as a constructed entity (Gould,

1996; Vehmas, 1999) and as a classification (Carlson, 2005) that has borne significant historical import on those who have been affected by its assumed categorical omnipotence. In this regard, there are two principal issues of concern. First is the notion of ‘intellect’ as a constructed entity. Despite significant scholarly challenges which will be outlined below, the notion of a measurable and hierarchically-arranged intelligence remains influential in academic circles. Indeed, the stances of popular bioethicists Singer (2011), Rachels (1986), and Kuhse (1995) continue to play a central role in bioethical debates in which people’s inherent ‘value’ is assessed according to demonstrable skill and intellect, indicators of the potential for a “‘normal’ and ‘full human existence’” (Vehmas, 1999, p. 43), thus having serious implications for people identified as intellectually disabled. Moreover, historical considerations also point to the emergence of the idea of rational thought as a determining factor in the assessment of human capability and worth (Stainton, 2008, 2004; Vorhaus, 2013). As Foucault (1988) indicates in *Madness and Civilization*, the development of the “tyranny of reason and the silencing of unreason” (Carlson, 2005, p. 134) was instrumental in securing the designation of the intellectually inferior. In the same way that disability scholars have pointed to the designation of the ‘marked’ and disabled body to ensure the existence of the non-disabled (Garland-Thomson, 1997; McRuer, 2006), so, too, have scholars indicated that the emergence of the “discourse of reason” (Stainton, 2004, p. 225) in the late fifteenth and sixteenth centuries allowed a “parallel discourse of unreason, reason’s *Other*” (ibid) to materialize. Further, as Borthwick (1996) has pointed out, some of the earliest, Darwin-inspired and racist explanations of intellectual disability adhered to the notion that ‘inferior’ forms of intelligence were part of the natural order of the biological universe: “These people were different not because they were like us, but because they were intact and complete specimens of a lower order of being” (p. 406).

As discussed in detail in Chapter Two, the notion of ‘intellect’ has historically undergone significant morphological transformations, particularly during periods of intense anxiety regarding the propagation of ‘unfit’ citizens, for example, during the eugenic period of the late nineteenth and early twentieth centuries (Allen, 1997; McLaren, 1990; Lamp, 2006; Radford, 1991). While these phenomena will not be re-iterated here, it is important to note that prominent eugenic ‘scientists’ during this time period, for example, Galton (1822-1911) in Britain, and Goddard (1866-1957) in the United States, were relentless in their pursuit of the identification of ‘feeble-mindedness’ through intelligence testing and other means. This was seen as a necessary and efficient way to contribute to “sound, well-informed state policy” (Porter, 1986, p. 18), and to assist in decision-making concerning “adaptation [or]... elimination” (Goddard, 1920 [1914], p. 3) of particular groups of people who were generally regarded as drains on the public purse and threats to the moral and physical integrity of the broader population. While the theorems and methods of these and other scientists have been roundly criticized—indeed, Goddard’s methods are preposterous by current standards (Gould, 1996)—this does not diminish the fact that their findings bore significant influence in the establishment of institutions for the ‘feeble-minded’ and in the referral of thousands of people to live the remainder of their lives there, phenomena that continued even long after Goddard’s work was considered suspect (Rothman, 1971). Indeed, as current scholars of institutionalization have indicated, standardized measures of intellect have had a pervasive and enduring influence within medical and educative circles, and continue to be used as tools to predict individuals’ potential for successful integration into modern society (Kliwer & Drake, 1998).

However, scientific assumptions regarding the notion of a fixed, measurable human intelligence have been questioned rigorously by at least three main bodies of scholarly work.

First, detailed historical interrogations have deconstructed the fallacy of a reified intelligence and have revealed the unsound justifications for the resultant assessment and segregation of people deemed intellectually inferior (see, for example, Allen, 1997; Gould, 1996; McLaren, 1990; Trent, 1994; Radford & Park, 1993a). These historical accounts challenge the scientific “argument that intelligence can be meaningfully abstracted as a single number capable of ranking all people on a linear scale of intrinsic and unalterable mental worth” (Gould, 1996, p. 20). Second, postmodernism has rigorously disputed the notion of an innate and measurable intellect, and has pointed to the arbitrariness of attempts to measure what is, according to feminist postmodern scholars in particular, diverse, socially- and culturally-situated knowledges (Fraser & Nicholson, 1990; Harding, 1993; Lather, 1991). Postmodernism suggests that no observation of the world is free of discursive embeddedness and that medical, legal, and supervisory discourse which dictates standards of intellectual ability and capacity is both constructed and fluctuating in nature (Corker & Shakespeare, 2002). Postmodern interrogation highlights the fallacy of intellectual demarcation as justification for segregation, suggesting that institutions for people designated intellectually inferior were founded on unsound and shifting logic (Carlson, 2005; Foucault, 1977). Third, contributions from disability scholarship have demonstrated the limitations of singular definitions of intellect which have historically served to exclude people with intellectual disabilities. For example, Vehmas (1999) points out that bioutilitarianists’ “intellectually emphasised normative concept of the human being and its quality of existence” (p. 41), a stance that justifies according more value to the life of a ‘normal’ human being than one with intellectual disabilities, is “erroneous and morally fatal because it leads to conclusions which are morally questionable” (ibid, p. 44). The “quantitative nightmare” (p. 44) and “hopelessly relativist” (p. 43) conclusions which arise when attempting to define

intelligence as it relates to an acceptable quality of living eventually leads to the realization that “intelligence and intellectual disabilities are... culturally constituted, essentially normative concepts... a product of social and cultural values and expectations” (ibid, p. 47). Besides Vehmas, the work of Inglis (2013), Shildrick (2008, 2002), and Vorhaus (2013) have all provided epistemological and ethical challenges to the notion that the ‘humanness’ of people with intellectual differences is questionable due to their apparent failure to meet Western normative standards of autonomy and reason.

As institutional survivors from this study have indicated, the construction of intellect—the arbitrariness of its measurement, as well as its conflation with socio-economic status, family size and background, and one’s place of residence—had significant impact on their designation as intellectually inferior members of the community and their resultant placement in long-term custodial care. In a succinct Foucauldian example of the discursive construction of intellectual disability, one of the survivors of an institution stated: “I don’t know why I went there. I was a normal person before I went there”, thus claiming that it was the institution and its disciplinary practices that brought him as a “retarded” [*sic*] person, into being. “I was normal. But we were all normal. And they locked... nobody wanted us in the society. That’s what we felt. I, nobody wanted us, so they locked us up, that’s the only reason I can think of”. Further, as some former staff and key informants made clear, there were many residents of long-term institutions who “should not have been there”, that is, the intellectual designation that had secured them a decades-long sentence to institutional care was, in later years, highly suspect, bringing doubt to the entire intellectual ranking and institutionalization enterprise.

The second principal concern in regards to intellect as a determining factor in processes of institutionalization is the need to interrogate carefully the “history and status of mental

retardation [*sic*] as a *classification*” (Carlson, 2005, p. 133, emphasis in original). Carlson refers specifically to the need to “unmask the self-evident nature of practices and categories” (ibid, p. 134), and to expose the *history* of intellectual disability, as opposed to its examination as a medically-framed condition. Drawing on Foucault’s work, Carlson notes that “the institution was the vehicle through which expert medical knowledge about feeble-mindedness could be generated” (p. 137), and that institutionalization, as well as intelligence testing, allowed “the emergence of a new kind of individual” (pp. 137 / 8). In a classic Foucauldian explanatory loop, the “mentally retarded” [*sic*] individual to which Carlson refers is discursively produced through the very mechanisms—the institution and the test designed to ensure he or she is placed there—that are designed to discipline and control them. That is, “the identity of the [intellectually disabled] subject is produced... because this identity meets certain requirements of contemporary social and political arrangements” (Tremain, 2005, p. 10). Or, in other words, “the sudden creation of [the] institution was not merely a response to a pre-existing problem, but was the way in which the problem itself was constituted” (Ingleby, 1983, p. 147). This interpretation of the creation of the disabled subject is a direct reversal of modernist explanations which rely on medical symptomatology to ‘explain’ disability, and suggests, rather, that the disabled subject does not exist until the categories and institutions built to classify and house them are themselves constructed. Thus, the ‘history’ of intellectual disability, and its construction as a category of impairment, is exposed. Rather than impairment embracing a specific embodied and constitutive condition, the production of the impairment supports the maintenance of the structures created to control them.

In the context of this study, this notion has important implications in regards to the manner in which families engaged, or did not engage, with their family member with a disability.

In the creation of the distinct classifications to which Carlson refers, boundaries emerge which demarcate specific groups of people. Once boundaries are established, parameters materialize around which people negotiate interactions with each other (McLaren, 2002). This is of particular significance here, as findings from the parents' group in particular indicate that effort was frequently made to ensure that engagement with the 'classification' of disability itself did not occur. That is, while some parents might have declared that they loved their child, they also made it clear that they were not going to interact with the broader 'category' of intellectual disability nor with some of the thornier issues that such an engagement might reveal. Having a limited and controlled relationship with one person with a disability is one thing; acknowledging that the boundaries between disability and 'normalcy' are more porous and complex than originally thought is quite another. For example, one mother was adamant that she was not going to be "Mrs. Retarded [*sic*] Mother of the Year" in relation to her daughter. While the biological connection between herself and her daughter could not be denied, this mother was clear that this embodied link would be the extent of her engagement with the bigger, more complex, and potentially unruly body of intellectual disability as a whole.

Further, the existence of segregated institutions made it possible for families to stay well clear of the boundaries between themselves and the unknown and seemingly unknowable group of people classified as intellectually inferior. Private and apart, institutions enabled this separation and allowed categorical distinctions to continue. The classification of intellectual disability and the physical structures within which classifications were embedded gave families the authority to decide the level at which they would engage with their child, or not, and the level at which they would engage with some of the more complex issues surrounding disability in general. Thus, it seems, some families' reluctance to interact with 'disability' had as much to do

with the fear of stepping over the boundaries of classification and the consequences that might incur, as it did with discomfort with the singular ‘inadequacy’ of their own child.

Last, a paradox inherent to this discussion should be noted. Ironically, the historical fluidity of intellectual disability as a classification meant that the authoritative response was essentially an attempt to pin it down both figuratively and literally—with specific intellectual designations, located behind walls, and with strict limitations regarding peoples’ ability to leave its confines. This “pinning down” secured family members into their various positions in the interactive terrain within which they engaged with each other, a notion akin to Bourdieu’s (1990) “field, an arbitrary social construct, an artefact whose arbitrariness and artificiality are underlined by... explicit and specific rules, strictly de-limited and extra-ordinary time and space” (p. 67). With families complying with the classifications given their son or daughter, and then barred for decades from opportunities through which these original interpretations might be challenged, families were not exposed to that same ‘fluidity’ that might have allowed them to see their son or daughter differently. Institutions fixed people into distinct categories of engagement; culturally and geographically separated from other sources of discourse and re-interpretations, the lengthy and arduous shift to seeing people with intellectual disabilities as whole, complete and complex human beings was not experienced by many families who placed their child in an institution

Family concerns

The preceding paragraphs have discussed notions of power and intellect in relation to the phenomenon of institutionalization in general, and to the findings from this research in particular. The section which follows will address in greater depth findings which relate specifically to one of the principal areas of study in this project, the impact of institutionalization on family relationships and understandings of disability. While the preceding paragraphs have

already touched upon some of the implications of institutionalization on families, some areas of discussion remain.

First, findings indicate that overall, institutionalization was an unhappy chapter in families' lives. Regardless of how highly families regarded the institution at which their child lived (and, as findings from the parents' chapter indicates, there were indeed some parents who felt that the institution had done a wonderful service to their family: "the impact was wholly positive... my daughter blossomed at Rideau Regional", most families indicated that the experience of institutionalization was not a positive chapter in their family history. As one sibling noted, "not one good thing came out of it", a sentiment repeated by all of the sibling participants to varying degrees. And while most of the parents, save for the one quoted above as well as one other, would agree that their child's stay in an institution was not a "good thing", most simultaneously framed it as an undesirable but essential part of their family's life together. Accordingly, in regards to those parents who placed their child in an institution, a crisis-like approach becomes evident which seems reminiscent of the war-defined era of their formative years: their family had been befallen by an unfortunate situation, the birth of a child with a disability, and while the removal of this child from the family was a difficult decision and in some cases, undesirable, it was also what 'one must do'.

What is of particular interest here is the distinction between families in regards to the root of the identified unhappiness. For those families who saw institutionalization as a viable and reasonable way to deal with the dilemma of a family member with a disability, the 'problem' within the family was firmly rooted in the disability. "Her biggest regret was Gord", said one sibling, noting that it was not his brother's institutionalization that had caused his mother to experience feelings of disappointment and loss, but the fact that his brother had been born with a

disability in the first place. Conversely, for several other families, the locus of the problem within the family was not the disability per se, but the decision to institutionalize and the resultant years of awkward separation and tacit struggles to deal with the emotional aftermath. In these families, the decision to institutionalize and institutions themselves were identified as the problem, as well as all the associated structures and means by which people were admitted and subjected to institutional processes.

This is an important distinction, one that informs observations of disability's current socio-cultural position. More than three decades of work in the disability rights movement, as well as huge strides in human rights in general have promoted broader understandings of the rights and responsibilities to which people with disabilities are entitled (Charlton, 1998; Rioux, 2003; Silvers, 1995). Moreover, the social model, which articulates that the 'problem' of disability is located not in the individual, but in the social and cultural barriers which prevent people's access to a full and meaningful life, has had significant influence in interpretations of disability, particularly in academic and advocacy circles (see, for example, Barnes, Mercer, & Shakespeare, 1999; Oliver, 1996; 1990; Thomas, 2002). Despite these gains, however, indications that the predominant socio-cultural understanding of disability as an individual problem located within the body remain. Contrary to the social model's insistence that the whole of society must be interrogated and reconfigured in order to institute real inclusion for people with disabilities, biomedical advances push disability, rather, further and further in the opposite direction, into the minute yet seemingly infinite world of genetic understanding and manipulation (Lizza, 2007; Scully, 2002; Waldschmidt, 2005; Ward, 2002). In reference to intellectual disability in particular, Carlson (2005) notes the "increasing (rather than decreasing) complexity of this category in light of the genetic revolution" (p. 135). Moreover, Scully (2002)

suggests that the quest for ever-more minute designations of disability via “biomedicine’s dependence on molecularity” (p. 54), does not necessarily encourage an appreciation for variations in human composition, but, rather promotes “the control of... deviations” (ibid). Thus, despite social model interpretations, as well as the proliferation of human rights frameworks over the past half-century which have encouraged the implementation of political and legal tools to ensure equality and inclusion at national and international levels (Oliver, 1990; Rioux, 2003), biomedical discourse continues to perpetuate the notion that disability is individually experienced at the level of the body.

This is of concern here in that individually-constituted understandings of disability wherein the problem is located in the person and is addressed via curative and rehabilitative approaches allow institutional models of care to flourish. When the ‘problem’ of disability is framed as the person with the impairment and not the systemic and structural mechanisms which prevent him or her from meaningful inclusion, then the imposition of a comprehensive and static model which encompasses all problematic individuals within its reach does indeed appear effective and reasonable. Indeed, institutions were regarded as the most efficient way to deal with an unruly and unpredictable population (Radford, 1991; Simmons, 1982). Conversely, when the problem is identified as a lack of structural supports for families and misunderstandings about disability in general, then the deficiencies and inhumaneness of the institutional model become apparent.

Further, the distinction between families regarding how and where they situated the locus of the ‘problem’ which their family was experiencing was reflective of the family’s discomfort with the possibilities that were available to them and of the desire to instill change. That is, two groups of parents—those who chose not to institutionalize their child, and those who

did but were not happy with that decision—felt a distinct unease with the situation at hand, and demonstrated the greatest involvement with measures undertaken to dismantle the entire segregated, institutional system. This generalized unrest, the sense that the institutional model being presented could not be the only way to meet the needs of their child and their family, was the motivation that fuelled their desire for change. This is not a surprising finding—indeed, moral and ethical unrest at both the personal and communal level has historically been an inspiration to the address of injustice (Young, 1990), yet it remains valid in current circles. Families who remain dissatisfied with existing supports and services are most frequently those who assume leadership in movements to instigate change (Manning, 2011).

The second principal area of findings from families indicates that, despite the individuality of each family and their response to the situation at hand, they were all ultimately part of the huge bureaucratized and politicized machine of institutionalization. As one of the key informants indicated “probably there are as many different impacts [of institutionalization] as there are families”, yet all were forced to negotiate with, or, at the very least, acknowledge a system which favoured the mass segregation of people identified as having an intellectual disability. While the influence of mechanisms of power in regards to families’ decisions to institutionalize a child has been discussed in an earlier section, a closer examination of the interplay between larger socio-political forces and the individual decisions that families made, is called for here. In this regard, a closer examination of Bourdieu’s (1990) notion of the *habitus* is helpful.

As Ignatow (2009) indicates, “the habitus is a holistic theoretical device incorporating two levels of analysis in one conceptual framework [:] the micro level, an actor’s bodily and cognitive habits, and ... the meso level, the other actors, practices, and institutions with which she

or he interacts” (p. 103). In this regard, the *habitus* is a useful analytical tool, as it posits that culture is both “structured internally by bodily and cognitive processes, and externally by meso- and macro-level phenomena such as societal discourse and class structures and positions” (ibid, p. 99). The notion of the *habitus*, therefore, acknowledges the influence of both socially- and discursively-produced expectations and representations of intellectual disability, as well as families’ internal negotiations with those representations in their decisions to institutionalize. Moreover, Bourdieu (1990) contextualizes the *habitus* as a historical process: it is “a product of history, produc[ing] individual and collective practices” (54). Further, it is “*embodied* history, internalized as a second nature and so forgotten as history—[it] is the active presence of the whole past of which it is the product” (p. 56, emphasis added). Simply put, Bourdieu suggests that actions undertaken by families to place their child in an institution could be explained in part by the confines of historical practices, already constituted and deeply embedded in societal systems and structures, felt at the level of the individual. Despite criticisms that Bourdieu fails to acknowledge the influence of collective and individual moral compasses (Lamont, 1992, as cited in Ignatow, 2009, p. 99), he makes a contribution in his consideration of both individual praxis and systemic forces.

In addition, Bourdieu’s work indicates an inherent irony. While suggesting that the *habitus* encompasses seemingly endless possibilities for action (p. 55), he also indicates the limits that our praxis actually endures. He states: “the *habitus* makes possible the free production of all the thoughts, perceptions and actions inherent in the particular conditions of its production—and only those... [there is an] *infinite yet strictly limited* generative capacity” (p. 55, emphasis added) for our actions. In regards to our purposes here, this exposes a tension that some families experienced in the aftermath of placing their child in an institution. Despite their

anticipation that institutional placement might actually garner them greater freedom, in particular from the demands of caring for their child and integrating him or her into the wider contexts of family and community, findings from this study suggest that many families were never released from the emotional hold of their child and of the decision they made. Indeed, in most cases, removing the child from the home resulted in a life-long burden of questioning and self-recrimination, a far cry from the freedom that they might have imagined. It appears that those who placed their child experienced the “strict limits of our capacities” at the “embodied” level to which Bourdieu refers; the physical freedom of the institution did not offer them the emotional or social freedom that they had anticipated.

To conclude this section on family considerations, I draw attention to one further observation that belies categorization with the issues mentioned above but nonetheless deserves attention. Some of the families who participated in this study revealed significant epistemological shifts in regards to their interpretations and understandings of disability. Those siblings whose brother or sister survived institutionalization, as well as those parents who did not look favourably on institutionalization, indicated that the meanings that they ascribed to disability underwent (and indeed, continue to undergo) significant changes as they witness the life of their sibling or child and continue to come to know him or her. This is particularly true of the siblings, who indicated that the interpretations of disability to which they had been exposed in their early years were gradually and consistently challenged as they came to know their brother or sister on their own terms. Connected to the experiences of false narratives as discussed in Chapter Eight, a phenomenon in many homes which had long-lasting and deeply-felt consequences, all of the siblings, and some of the parents, stated that this gradual coming-to-know process forced a profound shift in their understandings, a process which was frequently

emotionally taxing, and in more than one instance, has created significant family rifts. In particular, when siblings challenged their parents about the family narrative being used to justify institutionalization, this frequently led to both personal and family crises. Throughout, some fundamental insights have emerged.

First, those who were open to an altered understanding of disability recognized that the family member with the disability had not ‘changed’ in any fundamental way. Rather, it was the constructive processes and social discourse around the disabled person that had shifted, as well as the family member’s personal interpretation of that discourse, thus revealing the arbitrariness of the definitions and decisions in the first place. Second, siblings, as well as survivors and key informants, observed that a similar process unfolded in regards to the institutions. In the same way that people with disabilities do not ‘change’ and thereby become somehow more socially pleasing and acceptable, but rather that the interpretations around them change, institutions also do not fundamentally ‘change’. Despite authorities’ indications that institutions were undergoing significant structural changes in order to “better meet the needs of the residents”, these participants observed that at a very fundamental level, there was little difference in the model of care that was being offered. Despite massive architectural re-design and changes in staffing ratios, institutions remained places of incarceration, examples of a model of care that was outdated and inherently oppressive by nature.

What these brief examples point to is the ubiquity and power of the discourse used to frame both people with intellectual disabilities and the institutions which housed them. When siblings spoke of the ‘shifts’ they experienced in terms of their understandings of disability, they were really referring to an increasing awareness of the discursive production that had been put in place around their sibling, a discourse that had limited their capacity for understanding.

Frequently, it was this sometimes-sudden awareness that led to so much personal turmoil and familial breakage. When siblings ‘figured out’ the truth of the motivation behind their parents’ actions—that the decision frequently had as much to do with the parents’ desire to be removed from their child as it did with the child’s inherent weaknesses—the resulting crisis of trust led many siblings to feel unmoored, and indeed, abandoned within their own families.

Contributions to the field

Findings from this project provide several points of reflection relevant to the field of disability studies. First is the repeated observation that the discursive production of disability—that is, that the disabled subject is “gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, desires, [and] thoughts” (Foucault, 1980, p. 98, as cited in Tremain, 2005, p. 6)—has been, and remains, a principal contributing factor to the treatment and consideration of people with disabilities. This is not a new contribution to the field. Indeed, several disability scholars have commented on the construction of the disabled subject (Davis, 2010; Siebers, 2008; Tremain, 2005) as well as the need for the existence of disability in order to ensure the existence and longevity of the non-disabled, the ubiquitous and assumed centre of social, political, and cultural discourse (Garland Thomson, 1997; McRuer, 2006; Snyder & Mitchell, 2006). Further, as pointed out above, Tremain (2005) and Carlson (2005, same volume) have drawn helpful connections between Foucauldian theory and the emergence and maintenance of disability’s constructions within bio / power’s administrations. Moreover, activists and academics who first posited the tenets of the social model in Britain drew support from Marxist analyses which pointed to shifts from agrarian to capitalist modes of production as the principal reason for changes in critical interpretations of the value of contributions of people with impairments (Finkelstein, 1980; Oliver, 1996; 1990).

Where this research offers new insight is in its specific historic and cultural location. This project draws on the experiences of subjects who participated in mechanisms which created and sustained, and sometimes resisted, the subject of the ‘intellectually disabled subject’ and the institutions in which they were housed in a particular location and time period. Much can be learned by examining the historical conditions that allowed and encouraged these emergences to occur, as well as the factors that allowed their perpetuation for decades far beyond Williston’s urging in 1971 to close down all institutions for people with intellectual disabilities in Ontario. The roots of the designation of intellectual disability and the institutions built to house them in late nineteenth and early twentieth century Ontario have been well documented, and indeed there is a good deal of scholarly consensus in this regard. Most scholars would agree that eugenic fears (Allen, 1997; Lamp, 2006; McLaren, 1990), a burgeoning interest in genetic science as informed by Darwinian and Mendelian theories of heredity (Gould, 1996), as well as the emergence of mandatory and free public education (Simmons, 1982; Trent, 1994), all contributed to the identification of greater and greater numbers of ‘feeble-minded’ individuals, creating the need for locations within which to segregate and contain them (Radford, 1991; Radford & Park, 1993a, 1993b). Where this study diverges, however, is in its specific observation of the continuation of the institutional model in Ontario into the twenty-first century, primarily as a result of the lack of “clearly defined positive policy objectives” (Simmons, 1982, p. 27) and a lack of purpose other than the implementation of a segregated custodial model. The inertia embedded in Ontario’s historical treatment of people with intellectual impairments is an observation that should remain of interest in current political commentary, as it raises questions about existing models of care. That is, does the reluctance which informed so much of the past centuries’ dealings with the group of people designated ‘intellectually disabled’ continue to have influence in political

decision-making and cultural interpretations? Certainly the forty-year span from Williston's first admonition of Ontario institutions until their final and complete closure in 2009 is an indication of the extent of the apathy and inaction on the part of government. It is beyond the scope of this project to determine precisely how to implement political and community-based tools to ensure that the torpor which has characterized Ontario's treatment of people with disabilities does not continue. However, the historical excavation which this study attempts facilitates a genealogical Foucauldian query, that is, "what were the historical conditions of possibility for this problem in the present?" (Tremain, 2002, p. 33) That is, how can this study, based as it is on reflections of a particular phenomenon in a specific time and location, inform what is still generally perceived as a 'problem' within political and cultural circles? While the goals of this project do not specify attempts to answer these questions, it appears that a radical restructuring of what actually constitutes the 'problem' is called for. At the very least, this study suggests that the historical patterns and tendencies identified must be considered part of current understandings, interpretations, and political decision-making. Moreover, as survivors themselves indicated, there is room for imagining other possibilities. Walt stated, "They took away our vocation, they took away our dreams, our hopes, everything ... [but] it's not too late. We can still do something. We can get on with our lives". Quentin added, "We all benefit from the fact that people aren't in institutions. I feel that everybody can live in the community with support, whatever it happens to be... you just have to figure it out".

Where this project is most definitive is its endeavour to take these 'identified historical patterns and tendencies' and to determine their impact on family relationships and understandings of disability. One of the principal observations from this study is the profoundly negative impact that institutionalization had on people designated intellectually disabled.

However, as Radford (1991) notes, there is a lack of empirical narrative representation from survivors themselves regarding this experience. Moreover, this project strongly indicates that the oppression suffered because of processes of institutionalization were felt far beyond the immediacy of those incarcerated, and extended in ever-widening circles to many more thousands of individuals and families. While recommendations from authority figures in the mid-twentieth century were clearly of the mindset that to do away with the source of the problem was the best solution for the family concerned, the narratives to which I listened all indicated that the negative repercussions of the removal of a family member were, and indeed are, long-lasting and often traumatic. The “rupture” to which siblings referred, the regret which some of the parents indicated, the anger expressed by many over the inadequacy and inhumaneness of this model of care, all indicate that the impact of the decision to institutionalize was indeed felt by many, and for a very long time.

Further, this research speaks to an under-addressed area in the critical disability studies canon, that is, the history, concerns and narratives of people identified as having intellectual disabilities. There have been contributions in some areas, particularly in regards to human rights (Herr, Gostin, & Koh, 2003; Redly, 2008; Ward & Stewart, 2008; Young & Quibell, 2000) and issues of consent and capacity (Baylies, 2002; Scott et al., 2006). Indeed, the passage of the United Nations’ Convention on the Rights of Persons with Disabilities in 2008, in particular Article 12, indicates increasing international recognition of the need to address the fundamental issue of the right for all persons for recognition under the law. Further, work has been done on the ethical and moral implications of conducting research with people designated as having intellectual impairments (Rioux et al., 2013; Sample, 1996; Stalker, 1998; Swain et al., 1998).

However, there remains a tendency within the field to not account specifically towards the experience of people with intellectual disabilities within the community of people with disabilities in general. The reasons for this could be attributed to the relatively brief history of the disability rights movement, and the tendency to attribute less value to contributions from people identified as intellectually disabled. As Young (1990) suggests, social movements undergo maturational processes which include various stages of increasing (and sometimes decreasing) inclusivity. In light of the relative newness of the disability rights movement, it could be seen as occupying a developmental phase wherein the narratives and concerns of less dominant and seemingly less influential members are not as readily included as those who have assumed more prominent leadership roles. Just as the original leaders of the disability rights movement have been called to greater inclusion of the experiences of women with disabilities (Asch & Fine, 1988; Landsman, 1999; Morris, 1991; Crow, 1996) so, too must the absence of narratives of people with intellectual disabilities be accounted for. This absence raises questions regarding the assessment and interpretation of the value of people with intellectual disabilities even within disability activism and academia. In the same way that the feminist movement, “whose agenda involves portraying women’s strengths and competence... [and thus has] long ignored women with disabilities (Landsman, 1999, p. 149), it bears consideration whether or not disability rights activists have been afraid to include people considered intellectually less competent for fear of compromising a strong and capable public presentation.

Moreover, while narratives from this research indicate that people with intellectual impairments continue to assess themselves within the context of a ubiquitously normative culture, that is, they articulate their oppression primarily in relation to the able-bodied and ‘normal’ population, I propose that it is time to reconsider the demarcations within the disability

community itself. In the same way that postmodern assertions of fluidity and porousness between traditional boundaries of gender and embodiment have informed all manner of feminist, political and cultural studies (Gibson, 2006; Haraway, 1991; Kinsman, 2004; Price & Shildrick, 2002; Shildrick, 2008, 2002), perhaps it is time to reconsider the boundaries which have historically existed between ‘physical’ and ‘intellectual’ designations that have until now limited the contributions of people with intellectual impairments from more contentious areas of discussion and decision-making. While it remains to be seen where this fluidity might lead, the narratives provided by participants in this study suggest that considerations of people seen as ‘intellectually disabled’ must start to go beyond notions of protection and care, and forge ahead into more complex areas such as self-determination, citizenship, and secure access to social, labour, and economic rights. This undoubtedly raises some complex questions within the field. The ongoing cultural assumption of “aesthetic dissonance” (Agger, 1976, p. 20) with which many people with more complex disabilities are regarded continues to plague efforts to move discussions past notions of acceptance and tolerance, and into more intricate and complete praxes of inclusion. Perhaps this is a question that might guide discussions within critical disability studies into the twenty-first century.

Finally, to conclude this analysis, I return to questions posed within the early critical theory tradition (Phillips, 2000), helpful here in imagining where the findings and reflections emerging from this research might lead. Kant (1724-1804), although his reliance on reason and his faith in modernity are frequently considered suspect within the disabilities studies canon (Corker & Shakespeare, 2002), posited three useful questions in his philosophical investigations, incorporating critiques of epistemology and reason, of human action, and of judgement respectively: *What can we know? What should we do? and What may I hope?* (Phillips, 2000, p.

11 / 12). While it is my hope that the first question has been at least adequately addressed in the preceding chapters, I believe it is the last two that hold the potential to guide future discussions of issues and concerns that have arisen in this research, and I address them briefly in turn below.

Findings that have emerged from this research indicate that the historically-accepted response to the question,—“*What should we do?*”—requires a revisionist interpretation if the needs and rights of people with intellectual disabilities are to be recognized. That is, reflection on the history of institutionalization in the nineteenth and twentieth centuries, revealed via both textual examination and the empirical, narrative research conducted for this study, reveals that the question above has generally been interpreted to mean *What should we do **with**?*—suggesting that people with intellectual disabilities were at best something to deal with, the group as a whole a problematic and disposable entity. The ‘problem’ was both the person with the intellectual disability, as well as the question of what to *do* with that disability and the person in which it resided. And indeed, the institutionalization system offered a convenient and aesthetically pleasing solution to the question of ‘what to do with’, as it allowed an entire group of people to remain unseen and unheard for decades.

Contrarily, a revisionist interpretation of the question posed above would allow it to read instead-- *how should we do with?*—not merely how to get rid of, but how to embark on entirely new ways of viewing disability and intellect, not merely as messy deviations that must be incorporated into the mainstream, but as elements of diversity and richness from which the whole of society benefits. However, a further modification is required. While Kant and other early critical theorists might have determined the ‘we’ in the above questions to be a beneficent and caring entity, current interpretations reveal the oppressive structures embedded within distinctions between the ‘we’ and everyone else. The question remains—who, exactly, is the

‘we’ in the first place? As Young (1990) indicates, groups of people who have historically been oppressed continue to suffer from such distinctions, even when articulated as a ‘helping’ relationship between the powerful and the powerless, as is the practice in welfare democracies (p. 54).

And last, the question—*What may I hope?* Indeed, with the long-awaited closure of all the huge government-run institutions for people with intellectual impairments in Ontario, we might dare to imagine that there is much we can hope for. But, as participants in this study indicated, a good deal of work remains to be done. As Walt, one of the survivors of the institutions noted,

I don’t believe in group homes. I think we should call them
‘Peace at Last’ homes...like I said in my story, it says right
here—Peace at Last—if you’re going to have a home for
people with disabilities, I think you should call it not a group
home, because we don’t like group homes. I think it should
be called Peace at Last, because if you hear their stories,
you’ll know what they all went through.

Findings suggest that many of the survivors, still coming to terms with the emotional, social, and physical consequences of years spent in an institution are far from ‘peace at last’, and that many members of their families also continue to reconcile the losses and personal and familial difficulties experienced through institutionalization. While it is beyond this paper’s mandate to provide a definitive roadmap towards those places of peace, the experiences articulated here indicate that they will never be found in large, locked facilities, or in the forced segregation of Ontario’s institutional history, nor in denigrating constructions of intellectual disability. Rather,

this research indicates that a radical reconfiguration and re-understanding of the notion of intellectual disability is called for as part of the work of creating communities in which all members have a place.

Concluding Remarks

The following discussion is an attempt to bring the findings and analyses of preceding chapters to a summative conclusion, to remark briefly on some of the more prominent themes which have emerged consistently in this work, and to provide some thoughts regarding future directions in this area of study.

Throughout this study, various influences on families regarding their decision to place a child in an institution have been explored. Analyses from previous chapters suggest that a complex web of inter-related persuasions were at work, including the influence of materialist and economic factors within the larger scheme of modernist and capitalist production, social and political factors which shaped public discourse in the postwar era, as well as inter- and intra-personal factors which influenced people's view of difference in general and intellectual disability in particular. While this interplay between macro and micro forces makes it difficult to determine families' precise intellectual and emotional routes to the decision to institutionalize, it can be safely assumed that multiple factors and conditions were at work within each family's discernment. Our attempts to understand this process must therefore include appreciation for the complexity of pressures with which families had to contend.

While the existence of complexity is evident, certain issues remain unresolved. In particular, questions remain regarding why some parents chose to keep their child at home while others felt compelled to institutionalize. While this has already been briefly addressed, this research further indicates that a key determining factor was the parents' interpretation of disability and their openness to be challenged in that interpretation. That is, a feature in decision-making was whether or not and to what degree parents viewed disability as a pliable entity, its "meaning open to history's revisions" (Mitchell, 1999, p. ix). When parents and other family

members realized that disability might have a ‘history’ that has undergone adaptations according to the economic, political and social conditions listed above, rather than disability *being*, in its entirety, a subnormal condition, they were also more likely to comment on the fluctuating nature of institutionalization itself. Those who recognized the insecure construction of the deficits attached to their son or daughter were also able to discern the unstable foundation of the institution. Despite its high walls and impenetrable boundaries, the impermanence of the system was revealed, ironically through the weakness of the construction of the disability it was meant to house. Thus, the historicity of disability and of the institutions constructed to address it were key factors in parents’ discernment.

Further, as addressed in the sample section of the methodology chapter, findings suggest that socio-economic status and class played a role in parental decisions to institutionalize a child, although these decisions stemmed, interestingly, from variant social contexts. That is, while the sibling group and the parent group made it clear that the preservation of or aspirations towards an upper class lifestyle was a determining factor in parents’ decision to place their child in an institution, some of the participants from the survivor group indicated that, according to their recollections, the intervention of social welfare services played a role in their placement, suggesting that families from lower socio-economic situations possessed far less control in decisions concerning their families’ welfare than those of their wealthier counterparts.

Moreover, this study indicates that one of the principal tensions with which families had to contend included understandings of principles of self-determination. As was addressed in the previous chapter in the discussion of intellect and personhood, fundamental to many parents’ decisions to place their child in an institution was the belief that people with disabilities do not possess the capability to make appropriate decisions for their own care, or where they might

prefer to live. Only recently has this notion been challenged, and recent policy has taken some steps to ensure that people with disabilities have some say in the future direction of their own lives. However, as some of the participants in this study indicated, it is not safe to assume that the historical disregard for self-determination has been eliminated now that the institutional era is officially ended (although many of those same participants indicated that they do not consider that institutionalization has ended in practice). Tensions that frequently arise within forums of decision-making around people with intellectual disabilities have not necessarily disappeared with the abolishment of overtly unjust methods of care, nor do community models guarantee a resolution of those differences. Issues of informed consent, substitute and assisted decision-making, and respect for peoples' dreams and desires remain contested areas, despite significant changes in policy, in care provision, and in public perceptions of disability.

Moreover, this study has pointed to the strangely silent position that institutionalization has occupied in the history of the province. That is, once families had made the decision to institutionalize, the lives of people in institutions remained hidden, as did the narratives of the families who had made the decision to place them there. For decades, via its invisibility and hiddenness from mainstream culture, the 'problem' of the person with intellectual disabilities seemed resolved—unseen, and unheard. Very few people were actually in contact in any way with the institutions, save for the residents, some family members, and staff. As one of the parents in this study reported, "You didn't see children with Down syndrome in those days". According to her, the assumption was either they had not survived, or had been 'sent away'.

Despite its hidden nature, however, the institutional presence in Ontario's history and geography was vast, exemplified both in the array of fortress-like buildings on large tracts of rural land positioned throughout the province to ensure maximum geographic coverage, and in

the extent of their reach into the lives of thousands of people. In spite of this, however, people who experienced institutionalization have, until very recently, borne this formative piece of their personal and familial history in silence and alone. In short, institutionalization was a shameful and hidden undertaking. Further, this invisibility did not necessarily end when the institutions closed. Although families had been strongly encouraged to institutionalize their children, once this period ended in families' lives, either through death or deinstitutionalization, there was little avenue for discussion or the sharing of experiences. Indeed, in the silence that met so many people upon their leaving the institution, the problem remained 'theirs' with which to contend. Not until the launch of the class action lawsuit against the Ontario government by former residents in 2012 was there any movement towards a public accounting for what had happened, and a public reckoning that what had happened was wrong¹.

Despite the concealed nature of institutionalization and its absence from public discourse, however, a public text of justification for institutions' continued existence remained influential for decades in regards to generalized perceptions of intellectual disability. As long as institutionalization remained the principal strategy as a way to 'deal with' a problematic population, public views of people with intellectual disabilities were not required to change. People with intellectual disabilities remained, rather, a group of people the rest of the population did not have to account for or consider. From this perspective, the essentialist nature of institutional policies becomes evident: people who were unfortunate enough to have been born with a disability, or to be in a family within which this person was situated, bore the brunt of a system which encouraged exclusion and incarceration. This appears as one of the key findings of this research in regards to the impact of institutionalization on families: while the majority of people 'benefitted' from a system which conveniently removed a messy and unstable group from

the population, this categorical exclusion occurred at the expense of the emotional and psychological integrity of individuals and families. Institutional survivors and their families suffered the consequences of a system that was highly valued during mid-twentieth century conservative politics, a system within which many people were complicit. In this regard, parents' fidelity to and defence of the system, even many decades later, is really quite remarkable.

Further, this study sheds light on the problematization of disability, a practice exhibited but not exclusive to the particular time period encapsulated by this project, and reflection upon which offers some insight to policy considerations for the future. As a practice, institutionalization *requires* that people with intellectual disabilities be considered a 'problem' needing address. The institutions' survival was contingent on the construction of disability as a serious dilemma and on its identification in large groups of people, lending credibility to Ingleby's (1983) observation that the institution's emergence was the process through which "the problem itself was constituted" (p. 147). This is an observation that substantiates the notion of the instability and arbitrariness of institutionalization practices, and of the fluctuating criteria for the designation of intellectual disability and eligibility for institutional admission.

Moreover, as this study has indicated, large-scale attempts to 'solve the problem' of disability have inevitably resulted in a failure to address the needs and concerns of people with disabilities and those closest to them in a dignified and respectful way. Indeed, confronting intellectual disability as a problem to be solved, and then proceeding to address it under the rubric of a large-scale, uniform solution has historically done nothing to improve the lives of people with disabilities, nor to alter widespread and unhelpful social and cultural interpretations of intellectual impairment. Indeed, if policymakers are committed to ensuring that people with intellectual disabilities living in the community experience real inclusion, self-determination, and

a life with dignity and respect, serious consideration must be given to the mistakes implicit within practices such as institutionalization which perceive and treat disability within a “meta-narrative of deviance, lack and tragedy” (Corker & Shakespeare, 2002, p. 1). Rather, as Corker & Shakespeare suggest, the challenge lies in “how we build inclusive societies” (ibid, p. 2), wherein “local narratives” and “different social locations and histories” (ibid, p. 5) are acknowledged. While the current trend towards individualizing support for people with disabilities is considered by many to be a step in the right direction (Power, 2013; Van Loon et al., 2010), there is more work to be done in the dismantling of large, all-encompassing and inherently depersonalized strategies.

Further, while significant changes in both socio-cultural discourse and public policy have broken down much of the rhetoric which frames disability as a problem as well as the policy designed to address it, Young (1990) contends that various forms of oppression, including ableism “have not disappeared with a... discursive commitment to equality for all... but have gone underground, dwelling in everyday habits and cultural meanings of which people are for the most part unaware” (p. 124). Accordingly, the work to redress the wrongs suffered by people who spent years of their lives incarcerated against their will for no reason other than demonstrating difference must include what Young (1990) refers to as a “cultural revolution which also entails a revolution in subjectivity” (p. 124). In Young’s words, such a revolution would entail not a “seeking [of the] wholeness of the self” but rather, “we who are the subjects of this plural and complex society should affirm the otherness within ourselves, acknowledging that as subjects we are heterogeneous and multiple in our affiliations and desires” (ibid).

Last, no research project is complete without noting possible future research directions which have emerged through its completion. In this regard, this project indicates there is much to

be considered, and I present here a hopeful albeit partial list. First, survivors who participated in this study indicated their ongoing concerns regarding accessible, affordable, and respectable housing for people with disabilities, as well as access to meaningful and well-paid work, and the right to be included in all aspects of civic and social life. In this regard, work is needed to evaluate the extent of these issues in people's lives and to articulate strategies towards access in all senses of the word.

Second, the brief foray into the history of institutionalization which was necessary for this project indicates the potential for more work in this area. For example, references to the possibility of drug and other medical experimentation on residents of Ontario's long-term institutions for people with intellectual disabilities (see, for example, Simmons, 1982), corroborated by similar accounts of scientific experiments on residents at First Nations' residential schools, signifies the need for more investigate research. Other historical projects emerge, including, for example, the theorization of the use of former military bases to expand institutions for people with intellectual disabilities, and investigations into the theoretical and historical overlaps with residential schools.

Moreover, this research indicates a significant need for the theoretical address of notions of intellect and human worth within the context of a highly medicalized and intellectually sophisticated world. Despite huge strides in public acknowledgment of the contributions of human variation to civic and social life, ongoing exploration at the frontiers of genetic science in regards to the 'discovery' and identification of disability indicates a need for critical disability scholars to offer thoughtful and, where necessary, contrarian perspectives. Such articulation could also be valuable within an international context, as institutionalization and

other questionable forms of treatment for people with intellectual disabilities continue to exist in various locations.

Last, this research has focussed on the effect of institutionalization practices within families. To this end, survivors, siblings, and parents all indicated that no-one had ever asked them about their experience of institutionalization before. The silence of this history, in conjunction with the pain which many feared they would relive if they tried to talk about it within their own families, meant that many had not put words to this chapter in their family's history, ever. Despite the pain it invoked, recounting the narrative of separation was referred to by many as a helpful process, an acknowledgement that this did indeed happen. And thus, by extension, it was an acknowledgement of the brokenness encountered by hundreds of people: men and women, sisters and brothers, fathers and mothers, both within the institution and beyond its walls.

Endnotes

Introduction

¹ In the United States, the terms ‘developmental disability’ and ‘developmentally disabled’ are the more frequently used terms; in the United Kingdom, ‘learning difficulties’ is used.

Chapter One

² Ironically, the social and political arrangements which define the parameters of essential civil engagement are generally the mechanisms which exclude those who fall outside of pre-requisites of ‘normal’ functioning. For more on the irony of institutionalized discourse which serves to exclude people of varying abilities despite its stated intention, see Titchkosky, T. (2007).

³ Foucault’s primary site of institutional theorizing was the prison. However, his insights regarding the genealogy and praxis of institutions are helpful in the broad theorizing of institutionalization being addressed here.

⁴ This theoretical thread—that is, the rejection of the other / rejection of self—has been furthered by disability scholars who suggest that the putative fear of disability, and the regulations created to deal with it, is more accurately understood as a fear of one’s own limitations and the threat to corporeal stability. See, for example, Marks (1999), and Shildrick (2009).

Chapter Two

¹ For scholarly discussion of charitable responses to people with disabilities prior to the establishment of formalized and state interventions, see, for example, Metzler (2006); Jonsen (2000); Porter (1997); Scull (1979); Stiker (1999).

² See Shakespeare (2006) for a renewed discussion regarding the role of charity. He points out that as current neo-liberal regimes continue to withdraw state support for people with disabilities in the community, families and individuals are forced to rely on charitable donations in order to maintain a reasonable quality of life.

³ The intelligence score that Binet developed—the first in 1905, with two more versions being completed prior to his death in 1911—was meant, according to Binet, to act as an “empirical guide... with a limited, practical

purpose” (Gould, 1996, p. 181). Originally devised as an ascending scale describing a child’s “general potential” (ibid, p. 179), it was adapted in 1912 by the German psychologist W. Stern, who devised the notion of an intelligence ‘quotient’ by dividing a child’s score by his / her age (ibid, p. 180)—hence the current nomenclature ‘IQ’. Binet’s scales were significantly altered after his death by American psychologists and educators who used the test for sweeping assessments in both education and the military, purposes which had not been Binet’s original intention.

⁴ The name ‘Kallikak’ is a nomenclature devised by Goddard himself, which combines the Greek words for beauty (kallos) and bad (kakos). Goddard’s ‘finding’ that feeble-minded is passed on to subsequent generations stemmed from his observation of two family lineages who shared the same father in a rural area of New Jersey in the early twentieth century. Goddard (1939 [1912]) determined that the ‘bad’ line stemmed from a ‘defective’ mother, a woman of questionable intellect and morals; the ‘good’ line, from a more prosperous and worthy woman. Goddard, using only visual observation, noted: “... only one sure prospect was ahead, that [this family] would produce more feeble-minded children with which to clog the wheels of human progress” (p. 78).

⁵ Indeed, Gould (1996) suggests that the Stanford-Binet test has been so influential in educational settings that “thirty minutes and five tests might mark a child for life” (p. 207).

⁶ It is important to note that both Goddard and Terman publicly recanted some of their earlier findings and conclusions. Goddard stated in 1927 that the ‘feeble-minded’ were not a danger, need not be segregated, and that eugenic practices need not be applied to the ‘feeble-minded’ population. He did not, however, come to the conclusion that ‘feeble-mindedness’ and indeed all forms of intelligence might indeed be a socio-cultural construction (Gould, pp. 202-204); in 1937, Terman stepped back from his earlier dogmatic approach regarding innate intelligence and acquiesced to the influence of environmental factors (ibid, pp.221- 222).

⁷ There is historical evidence that when schooling in North America became public and mandatory, the numbers of identified ‘feeble-minded’ children rose dramatically (See McLaren, 1990, pp. 28-45; Trent, 1994).

⁸ The *Sexual Sterilization Act* became law in Alberta in 1928 and in British Columbia in 1933. In Alberta, much of the support for the passage of the bill came from farmers, who were concerned about the increase in

population of recent Slavic immigrants (McLaren, 1990). At the time of their passage, the presiding physician needed consent from the parents or guardians of the ‘feeble-minded’ individual in order for the procedure to go ahead. Within a few years, however, this consent was deemed unnecessary, and thus involuntary sterilization became an acceptable, if tacit, practice. These bills were not officially repealed until 1972. In Ontario, while there was no official legislation approving sterilization procedures during this time period, McLaren (1990) suggests that involuntary sterilization took place in government-run institutions well into the 1980s.

⁹ A contemporaneous note is worth mentioning here. Scholars suggest that the practice of barring people who are seen as potentially disruptive and depletive within the Canadian narrative of ongoing growth and development is a persistent discursive thread which remains firmly entrenched within Canadian immigration policies, and that vigilance and critique of these policies remains essential (Chadha, 2008; McLaren, 1990; Menzies, 1998; Thobani, 2007).

Chapter Three

¹ Scull is particularly helpful here. Although much of his work is based on the British experience and deals with the ‘mad’ population, and not with people with intellectual disabilities per se, he contributes to the discussion in regards to his incisive analysis of capitalist forces which had an impact on the rise of state-run institutions in the eighteenth, nineteenth, and early twentieth centuries.

² It is noteworthy that while both Trent and Scull analyse the development of institutionalization within a socio-economic framework, they deal with different populations; that is, the ‘feeble-minded’ and the ‘mad’ respectively. Radford (1991) suggests that, in the late twentieth century, there existed in the “asylum literature” (p. 449) a tendency to interrogate the historical development of institutions from a broad perspective, and that there had been only “peripheral” attention to the specific history of institutionalization of people with intellectual disabilities. Radford suggests that scholarship must be attentive to the convergences and divergences that exist among and between different groups of people affected by processes of institutionalization. In particular, he suggests that greater attention be paid to the institutional history of people with intellectual disabilities. It appears that some authors have taken up this challenge (see, for example, the more recent examples of Chupik & Wright,

2006; Strong-Boag, 2007; Wheatley, T., 2013). Thus, the initial, rudimentary but nonetheless crucial distinction between those able to contribute productively to a capitalist economic system, and those who were not, could be expanded to acknowledge the increasingly minute distinctions between various groups of 'deviant' people, a phenomenon that continues today in the hyper-categorization of various forms of difference.

³ While my references to people who are 'feeble-minded' refers specifically to people who would currently be considered people with intellectual disabilities, at the time of the establishment of institutions, this categorization frequently included people who had cerebral palsy, epilepsy, etc. For more on the indefinite boundaries between different groups of institutionalized peoples, please see Ferguson (1994), *Abandoned to their fate*, Chapter one, (pp. 1-19), Philadelphia: Temple University Press; and Trent, (1994), *Inventing the feeble mind*, Chapter one, (p. 7-39), Berkeley: University of California Press.

⁴ While Scull (1979) notes that by the middle of the nineteenth century in the UK, people considered mad had, for the most part, been well distinguished from other marginalized groups of people (p. 113). However, Simmons (1982) and Williston (1971), writing about institutionalization in Ontario, note that in the earliest days of institutionalization here, people were often grouped together. Indeed, Simmons notes that this blurring of boundaries continued to exist throughout the deinstitutionalization process, as hundreds of people with intellectual disabilities were simply re-located to other, smaller institutions, such as nursing homes (pp. 235-239).

⁵ Some of the more prominent examples include S. G. Howe's "experimental school for idiots" (Ferguson, 1994, p. 45), founded in Boston in 1848; H. B. Wilbur's private school for the feeble-minded, established in his home town of Barre in the same year (ibid); and the Vineland Training School for Boys and Girls, established in 1888 in Vineland, New Jersey, which in 1906 became a headquarters for intelligence testing and investigations into eugenic principles. For detail, see Ferguson 1994; Simmons, 1982; Trent, 1994; Tyor & Bell, 1984). More detail regarding the establishment of institutions in Canada will be given in the next chapter.

⁶ It is important to note that this is the historical juncture at which the Orillia Asylum for Idiots was established, in 1876. Thus, as Simmons observes, the Orillia institution, and thus all institutions for people with intellectual disabilities in Canada, never seriously embodied the optimistic ideology of the reform movement.

While Simmons notes that the educational model did not entirely disappear, even in Orillia, from the outset, the institution which was to become Huronia was primarily defined by an asylum approach.

⁷ McLaren (1990) explains the dynamics at play in Ontario and Quebec's reluctance to officially adopt sterilization policies. In both provinces, strong opposition to sterilization from influential groups of Catholic constituents (p. 125) prevented the provincial governments from fully implementing eugenic policies, despite a well-organized campaign initiated primarily from the medical and academic communities. Radford (1991) notes, however, that although Ontario officially opted for segregation as opposed to sterilization in its policy for dealing with the 'feeble-minded', "sterilization was undoubtedly carried out in many instances" (p. 452, with reference to McLaren, p. 163).

⁸ The Orillia Asylum was the cornerstone for all of the institutions which eventually came to prominence in Ontario. However, it was several years before new institutions of the same size and stature as Orillia were established, most notably, the Rideau Regional Centre at Smiths Falls in 1951, and Cedar Springs near Chatham in 1961 (Williston, 1971). Details of the development of institutions in Ontario will be discussed in the next chapter.

⁹ At present, this exploitation is seen in the guise of sheltered workshops, as people with intellectual disabilities fulfill terrifically mundane roles, such as stuffing advertising pamphlets into envelopes that are essential for the running of the market economy as it currently functions.

¹⁰ Alongside Ferguson's observations of the poor treatment suffered by people with intellectual disabilities whilst abandoned to almshouses of the mid-nineteenth century, is the notion of the distinction between the 'worthy' and 'unworthy' poor (Rioux & Zubrow, 2001). Since the English Poor Laws, there has been increasing "entrenchment" (p. 156) of the distinction between the 'worthy' and the 'unworthy' poor (p. 155). People with disabilities who are seen to have acquired their disability through "individual misfortune" (ibid) have, in more recent history, been categorized as 'worthy'. However, this boundary is a "social and legal construct" (p. 156) which shifts according to fluctuating notions of public responsibility and obligation (p. 157). While current definitions frequently position people designated as disabled as 'worthy', particularly if the individual is seen as not being responsible for his or her 'condition', historic connotations of disability with other, less favourable

categorizations which are deemed a result of personal or moral failure, have resulted in ‘unworthy’ designations, and, accordingly, a far less favourable public response.

Chapter Four

¹ The first *asylum* to actually be opened in Ontario was in 1841 (Reaume, 2000) at the Old York Jail in Toronto, “in which there were no specific provision for retarded persons” (Williston, 1971, p. 27). In 1850, the refurbished and larger “Provincial Lunatic Asylum” was opened in Toronto (Reaume, 2000); by 1859, a branch had been established in Orillia. While this institution soon closed down, one was established in London in 1873, specifically for the feeble-minded. When demand for services in London exceeded its capacity, a new institution, originally intended for feeble-minded children, was re-established in Orillia in 1876 (Williston, 1971).

While the official name of the institution in Orillia at the time of its closing was ‘Huronian’, many of the former residents, staff, and family members simply refer to it as ‘Orillia’. Accordingly, there are several instances in the text where I refer to this particular institution as ‘Orillia’.

² This figure (sixteen) refers to the principal, ‘Schedule 1’ government-funded institutions for people with intellectual disabilities that existed in Ontario prior to deinstitutionalization, which began with the closing of the Nipissing Centre in North Bay in 1978. Schedule 1 facilities were institutions which were completely funded and administered by the provincial government—initially the Department of Health, then the Ministry of Health, and finally the Ministry of Community and Social Services (1974), where ministerial services for people with intellectual disabilities continue to reside. This figure does not include the generally smaller ‘Schedule 2’ facilities, which were financed by the province but were administered by local boards and community agencies, nor does it include privately-run institutions (Government of Ontario; 2012; Simmons, 1982; Williston, 1971).

³ It is interesting to note at this point (although this issue is discussed in greater detail in the chapter text) that the largest increase in the actual number of institutions occurred between 1950 and 1970 (see Table 2), a time period which also marked the beginning of concerted efforts by some parents to secure equal access to schools for their children with intellectual disabilities, and for increased government support for community-based programmes. The construction of two of the largest institutions, the Ontario Hospital School at Smiths Falls

(Rideau Regional Centre) and the Ontario Hospital School at Cedar Springs (Cedar Springs Regional Centre)

occurred during this time period, in 1951 and 1961 respectively, as did the refurbishing of abandoned facilities, such as army bases, in order to secure more institutional 'beds' for people with intellectual disabilities. Further, it is important to note that many of the institutions discussed in this chapter have had more than one name throughout their history. Accordingly, I have attempted to use the name that was in use during the time period being discussed, and to indicate their revised names where appropriate.

⁴ H. G. Simmons (1982) has, to date, written by far the most extensive and comprehensive analysis of the development of institutionalization for people with intellectual disabilities in Ontario. As such, this chapter draws heavily from his work. While I have attempted to bring in the analyses of other authors and historical records, Simmons is my primary point of reference in analysing the developments particular to this chapter.

⁵ It is notable that for the first fifty years of its history, the asylum in Orillia had only two superintendents, A. H. Beaton, and J. P. Downey. This suggests that their particular regard for people with intellectual disabilities, and the policies to which they adhered, remained firmly in place for almost five decades. Knowing the close working relationship that these men had with the provincial governments at the time (Simmons, 1982) helps to explain the lack of movement in government policy around people with disabilities and institutionalization processes throughout the first third of Orillia's existence.

⁶ The institution at Smiths Falls, initially called the Ontario Hospital School, Smiths Falls, was originally designed to hold two thousand, four hundred residents, although its ultimate capacity was slightly less than that (Radford & Park, 2003). The Ontario Hospital School for Retarded Children at Cedar Springs was also originally designed to hold two thousand beds; eventually, plans were modified such that the maximum population was around one thousand (Simmons, 1982).

¹ It is important to note, however, that despite increasing rates of admission to government facilities during this period, and the dearth of community support, large numbers of people with intellectual disabilities remained at home with their families. Indeed, some historians (see, for example, Chupik & Wright, 2006, Clarke, 2006, Ferguson, 1994) have pointed out that while institutionalization has received greater attention in the

academic literature, the majority of families resisted the impetus to institutionalize their children and chose instead to keep them at home. Ferguson (1994) claims that “even at the height of the eugenics era, less than ten percent of the identified population of mentally retarded people was actually confined in e large, public institutions” (p. 10).

² These include the Northwestern Regional Centre (Thunder Bay, 1974); Bluewater Centre (Goderich, 1976); Nipissing Regional Centre (North Bay, 1975); St. Thomas Adult Rehabilitation and Training Centre (St. Thomas, 1975); and the St. Lawrence Regional Centre (Brockville, 1975—see Table 2).

³ The Conservative Party in Ontario officially changed its name in 1942 to the Progressive Conservative Party, in response to broader public interest in more liberal social welfare policies (Guest, 1999). The party re-adopted its original name in 2003, in a return to a more austere, right-wing ideology (Keil, 2002; Klassen & Buchanan, 2006). In order to best represent these shifts in nomenclature, which nonetheless indicate virtually the same political party, I will henceforth use the term Conservative/ Progressive Conservative Party (C/PC), despite its lack of brevity. The Conservative/ Progressive Conservative Party held power in Ontario from 1905-1919; 1923-1934; 1943-1985; and 1995-2003. Note the particularly long span from the end of the Second World War until the mid 1980s.

Chapter Five

¹ Thanks to Geoffrey Reaume for the idea for this title.

² Uppal, Kohen & Khan (2007) suggest from Statistics Canada 2001 census findings that 2.8% of the population are designated as having an intellectual or cognitive disability. This figure is consistent with WHO (2010) estimates of “somewhere between 1% and 3 %” (p.4). If Uppal et al’s figure is assumed to have been relatively consistent since the middle of the twentieth century, despite alterations in designation, and given that the population of Ontario in 1950 was approximately 4,500,000 people (Statistics Canada, Table 051-0005), then Simmons’s figure for 1950 of 3,035 people living in a facility for people with intellectual disabilities (p. 316) in Ontario does indeed indicate that there were many hundreds of children so classified who were living with their families.

³ This is not to say that the Soviet Union was not a driver in the escalating tensions and military stock-piling throughout the Cold War. I am suggesting, rather, that within North America, the political and social manifestations of the Cold War as put into place via government policy and regulation was primarily influenced by the strategies and political manoeuvring emerging from the United States. For more on Canada-U.S relations during this era, see Whitaker (2004).

⁴ Elaine Tyler May (2008[1988]) provides an extensive explanation of the term *containment* and its uses in *Homeward bound: American families in the cold war era*. New York: Basic Books. For other references to containment, see also Iacovetta (2006), Kinsman (1996), and Cavell (2004).

⁵ There are varying opinions regarding the official ‘start’ of the Cold War. Whitaker & Marcuse (1994) note that the anti-communism of the Cold War was a continuation of sentiment already well-established in the twentieth century (p. 11), and that tensions between the United States and the Soviet Union were firmly established by the conclusion of the Second World War, including a “stiffening of distrust in Canadian [public] opinion” (p. 12). Brookfield (2012), however, suggests that 1949 is the official start of the Cold War. In that year, the Chinese civil war ended with a communist party victory, and on 29 August, 1949, the Soviet Union successfully tested an atomic bomb, the United States thus “losing its monopoly on atomic weapons” (p. 30).

⁶ Thanks to Nora Groce for this idea.

⁷ Despite significant shifts in understandings of disability, and policy concerning the care and livelihoods of people with disabilities over the past sixty years, research from professional disciplines such as nursing and psychology continues to prioritize the impact of the disabled child on the remainder of the family; that is, it problematizes the concerns of the family within the individual with the disability. For example, see Bailey et al (2006); Blacher et al (2005); Freedman & Boyer, 2000; Jones, J. & Passey (2004); and Reichman, Corman & Noonan (2008). Notable exceptions, of course, have emerged in the last thirty years from the disability studies literature, wherein accounts of home life written by people with disabilities have begun to re-calibrate perceptions of the ‘effect’ of disability on the home and family life. See, for example, Jones, K. (2007), and Odell (2011).

Introduction to Part II

¹ The term ‘survivors’ to denote people with intellectual disabilities who have lived in institutions (as well as those from the mad community who have had to negotiate equally complex and oppressive systems) is considered contentious in some circles, particularly in light of recent class action lawsuits launched against the Ontario government for mistreatment at government-run institutions for people with intellectual disabilities. I use ‘survivors’ here with acknowledgement of the self-naming undertaken by members of these communities who are now speaking publicly about their experiences.

Chapter Six

¹ The first concerted call for the use of an emancipatory framework for disability research came in a 1992 edition of *Disability, Handicap & Society* 7(2); *Special issue: Researching disability*. In the introduction, editor Len Barton states: “...these papers raise fundamental questions about the nature and purpose of research and in what ways such activities can be underpinned by effective empowerment. Thus, this whole issue is set within the broader context of emancipation, choice, and social justice” (p. 99).

² Mertens (1997), who has written extensively on research paradigms and methodology within education and psychology, categorizes research with people who have traditionally been marginalized, such as people with disabilities, within an emancipatory paradigm (p. 3). Bearing in mind the four characteristics of the emancipatory paradigm that Mertens specifies (that is, i) places importance on the lives and experiences of the diverse groups that, traditionally, have been marginalized; ii) analyses how and why inequities based on... disability are reflected in asymmetric power relations; iii) results... are linked to political and social action; and iv) uses an emancipatory theory to develop the program theory and the research approach” [p. 18]), it is clear that her model aligns strongly with that proposed from researchers in the disability community who, in agreement with the principles of the disability rights movement, began in the early 1990’s to advocate for emancipatory research within disability studies (Oliver, 1992).

³ The process of sending out completed transcripts and asking participants to take note of any errors resulted in an interesting side-note: one of the former staff who participated in this project sent his transcript back

with heavy corrections to its grammar and sentence formation. It seemed this participant was uncomfortable with the written evidence of our less formal ways of speaking when in conversation, and felt obliged to offer ‘corrections’ to the natural hesitations and grammatical blips that appeared in the transcript.

Chapter Seven

¹ All names used are pseudonyms.

Chapter Nine

¹ Simmons (1982) refers to class distinctions in regards to who were being sent to institutions. He notes (pp. 148-159) that middle-to-upper class families often used “whatever influence they had with their local MPPs in order to jump the queue” (p. 148/49) for admission. However, he also notes that children from lower-class families whose care had been assumed by the state were frequently forcibly removed from the family home via conflated assumptions linking poverty, social status, and intellectual incapacity (pp. 65-109).

Chapter Ten

¹ Simmons (1982) notes that it was common for more than one generation of families to work at the same institution, an observation also noted by some of the key informants interviewed for this study. This was particularly true when institutions were located in small towns or rural settings.

Chapter Eleven

¹ While community living is currently the most accepted model for people with intellectual disabilities, vestiges of institutional living remain active in Ontario, as one of the former staff interviewed for this project pointed out. He noted that facilities such as the Thistletown Regional Centre and Oakdale are examples of facilities for people with intellectual disabilities that could be considered institutions, as they have more than nine beds and are locked.

² Prior to the final institutional closure in 2009, some survivors who had already moved to the community spoke of a fear of being returned to the institution should they make known the full extent of how they were treated while behind institutional walls.

Concluding Remarks

¹ In September 2013, the Ontario provincial government announced a financial settlement in the Class Action lawsuit which had been launched against it by two principal litigants on behalf of all people who had lived at Huronia, Rideau, and Southwestern Regional Centres for mistreatment and abuse. As part of the settlement, the Ontario government issued a formal apology to all former residents on December, 9th, 2013. The settlement and apology received a significant amount of media attention, a contrast from the silence which has historically surrounded the institutions.

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Appendix A: Sample Consent Form

Note: This is a sample of the written version; oral version involved verbal explanation of identical information

Date:

Study name: *Narratives of separation: Institutionalization, families, and the construction of difference*

Researcher: Madeline Burghardt, PhD candidate, Critical Disability Studies, York University.

Contact information: e-mail: mb0612rm@yorku.ca

Please Note: An oral informed consent process will be undertaken if a written consent form is deemed inappropriate or inaccessible to participants (please see attached oral version).

Purpose of the research: The purpose of this research is to examine familial understandings of family relationships, as well as their understandings of disability, when a family member with intellectual disabilities has been institutionalized for an extended period of time. This research will consist of in-depth, qualitative interviews with people who were institutionalized in government-run institutions in Ontario after WWII, with parents, with siblings, and with caregivers who worked in Ontario institutions during the specified time period. The research is in partial completion of a PhD in Critical Disability Studies at York University, and the findings will be presented orally and in writing at the researcher's dissertation defence at the completion of the study.

What you will be asked to do in the research: Participants will be asked to participate in one in-depth interview concerning their understandings of family relationships and their understandings of disability in the context of either i) being institutionalized in a government-run institution or ii) being a parent or a sibling of someone who was institutionalized or iii) being a caretaker in an institution. The interview will be audio-recorded and is projected to take between one and two hours. Participants will be given reports (written, and verbal if requested) of transcribed interviews and the final research report. Changes to transcribed interviews will be made if requested by participants.

Risks and discomforts: Some emotional discomfort may occur due to the nature of the research questions—i.e. the experience of institutionalization, and the impact this has had on the family. In light of this, participants can withdraw their participation at any time and can refuse to answer questions if desired (see below). Further, the researcher has enlisted the support of several community agencies who have agreed to provide psychological support and counseling should participants feel the need to process their narrative beyond the research setting. The list of supportive agencies is attached.

Benefits of the research: By reflecting on the impact of government policy, this research may contribute to future policy decisions that affect people with disabilities and their families. This research may have relevance in the dismantling of institutionalization practices in other parts of the world. This research may be of emotional benefit to family members who reflect on a particular time in their family history.

Benefits to participants: Participation will assist in the completion of a study which may have positive policy implications for people with disabilities and their families in the future. Participants will be able to reflect on a period of their lives in a safe and supportive setting.

Voluntary participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision to not participate, or to discontinue your participation, will not influence your relationship with the researcher or with staff of York University, either now or in the future.

Withdrawal from the study: You may stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher, York University, or any other group associated with this project. In the event you withdraw from this study, all associated data collected will be destroyed immediately.

Confidentiality: All information that you supply during the research will be held in confidence. Interview documentation and recording will not be associated with identifying information. Your name will not appear in any report or publication of the research. Data will be collected via audio tapes, with some handwritten notes for clarification if necessary. Audio and paper data will be safely stored in a locked cabinet in the researcher's home office and only the researcher will have access to this information. Recruitment and identifying information will be stored separately from the research data. Any data that is analysed electronically will be encoded and encrypted, and only the researcher will have access to the electronically stored data. The data will be kept for one year after the completion of the study, at which time the data will be destroyed. Confidentiality will be provided to the fullest extent possible by law.

Questions about the research: If you have questions about the research or about your role in the study, please feel free to contact me at (416) 537-5957 or mb0612rm@yorku.ca, or my Principal Supervisor, Dr. Marcia Rioux, mrioux@yorku.ca. If you have questions about this process or about your rights as a participant in this study, you may also contact the Critical Disability Studies Graduate Program Office at (416) 736-2100 x 44494, or gradcds@yorku.ca.

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethic Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University, (416) 736-5914, or e-mail ore@yorku.ca.

Legal Rights and Signatures:

I, _____, consent to participate in *Narratives of separation: Institutions, families, and the construction of difference* conducted by Madeline Burghardt. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

To be filled out by participant:

Name of participant

Signature of participant

Date

To be filled out by Principal Investigator:

Name of principal investigator

Signature of principal investigator

Date

Appendix B: Community Agencies and Support Services

Note: Prior to the beginning of the research project, all of these agencies had confirmed support for study participants should the need arise.

- Institute of Family Living
3080 Yonge Street, Toronto
(416) 487-3613
Contact: Diane Marshall
Family, individual, and couple counseling, not covered by OHIP, may be covered by extended benefits.
- Community Living Ontario
240 Duncan Mill, Toronto
(416) 447-4348
Does not offer counseling services directly but can provide links to local associations.
- Community Living Toronto
30 Birch Avenue
(416) 963-8656
Informal counseling, no cost; referral to social service professionals if needed
- Developmental Services Ontario
855-372-3858
- Surrey Place
2 Surrey Place, Toronto
(416) 925-5141
Intake number is through Developmental Services Ontario: 855-372-3858.
Individual counseling for people with developmental disabilities; self-referral
- Bereaved Families of Ontario,
36 Eglinton Avenue West, Toronto
(416) 440-0290
Peer mutual support for relationship loss, particularly for spousal loss and bereaved parents.
Non-profit service, no cost
- The Canadian Centre for Bereavement Education and Grief Counseling
80 Carlton Street, Toronto
(416) 926-0905 on Tuesdays, Wednesdays, and Thursdays.
Contact: Pam Fitzgerald
Private grief, bereavement, and loss counseling for families and siblings.

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- Family Services Toronto
www.familyservicetoronto.org
355 Church Street, Toronto
(416) 595-0307
Intake phone number: (416) 595-9618
Family, couple, and individual counseling
Payment based on income; sliding scale; may be covered by extended benefits.
 - Montage Support Services, Community Support Division
(416) 780-9630, ext 233
Access through Developmental Services Ontario, 855-372-3858
Montage services will connect individuals to counseling and community services.
 - William Cooke Counseling
(416) 762-0330
Experience with people with intellectual disabilities living through deinstitutionalization process. Sliding scale; not covered by OHIP, may be covered by extended benefits.

Appendix C: Survivor Demographics

* all names are pseudonyms

¹denotes sister of sibling indicated in Appendix C

²denotes brother of two siblings indicated in Appendix C

Participant	Date of interview	Location of interview	Relationship to Institutionalized Individual	Age at time of interview	Occupation	Comments
Male, Quentin*	17 Sept, 2012	Participant's home	self	72 years at time of interview	Advocate for disability rights	Admitted to SWR 1960; age c. 18; lived there 18 yrs
Male, Walt	20 Sept, 2012	Participant's home	self	59 at time of interview	Advocate; various jobs	Admitted to RRC c. 1958, age 5; lived there 20 yrs
Female ¹ , Hilary	1 Nov, 2012	participant's home	self	67 at time of interview	Employed at day programme	Admitted to HRC c. 1948; age c. 5; over 30 yrs
Male, Bob	1 Nov, 2012	Agency office	self	51 at time of interview	Caretaker at high school	Admitted to HRC c. 1973, age 12, lived there 9 yrs
Male, Calvin	20 Nov, 2012	Agency office	self	65 at time of interview	Door person at day programme	Admitted to RRC 1955, age 8; lived there 23 yrs
Male, André	20 Nov, 2012	Agency office	self	71 at time of interview	Retired from day programme	Admitted to RRC 1955, age 14; lived there c. 20 yrs

Participant	Date of interview	Location of interview	Relationship to Institutionalized Individual	Age at time of interview	Occupation	Comments
Female, Anna	30 Jan, 2013	Participant's home	self	54 at time of interview	Advocate for disability rights	Admitted to HRC 1965, age 7; lived there 13 yrs
Male ² , Gord	21 March, 2013	Agency office	self	75 at time of interview	Retired restaurant employee	Admitted to HRC 1953, age 15; lived there 23 yrs
Female, Irene	30 April, 2013	Researcher's home	self	59 at time of interview	Various manufacturing jobs	Admitted to HRC 1961, age 7; lived there 9 yrs

Appendix D: Sibling Demographics

¹denotes brother of survivor indicated in Appendix B; ²denotes brother and sister of survivor indicated in Appendix B; ³indicates daughter of parent indicated in Appendix C; ⁴denotes sisters, daughters of parents indicated in Appendix C.

Participant	Date of inter.	Location of interview	Relationship to institutional'd individual	Age at time of interview	Occupation	Comments
Female, Doris	1 Aug, 2012	Researcher's home	Sister	59 at time of interview	College instructor	10 yrs old when brother, age 5, was institutionalized
Female, Pauline	6 Sept, 2012	Participant's home	Sister	64 at time of interview	University professor	15 yrs old when sister, age 5, institutionalized
Female, Stephanie	18 Sept, 2012	Participant's home	Sister	64 at time of interview	Social worker; advocate; activist	4 yrs old when infant brother was institutionalized
Male ¹ , William	29 Nov, 2012	Work office	Brother	73 at time of interview	High School principal	Approx 11 yrs old when sister, age c. 5, institutionalized
Female, Erin	21 Jan, 2013	Participant's home	Sister	45 at time of interview	ED of church-based programme	4 yrs old when brother, age 2, institutionalized
Female, Geraldine	4 March, 2013	Participant's home	Sister	64 at time of interview	psychotherapist	Approx 6 yrs old when brother, age 3, institutionalized
Male ² , Gregory	9 April, 2013	Participant's home	Brother	70 at time of interview	retired	Age 10 when brother, age 15, institutionalized
Female ³ , Fiona	23 April, 2013	Participant's home	Sister	49 at time of interview	Freelance consultant ; disability advocate	Age 8 when brother, age 7, institution'd
Female ² , Patricia	25 April, 2013	Participant's home	Sister	73 at time of interview	retired	Age 13 when brother, age 15, institutionalized

Particip't	Date of inter.	Location of interview	Relationship to institutional'd individual	Age at time of interview	Occupation	Comments
Female ⁴ , Michelle	25 June, 2013	Participant's home	Sister	56 at time of interview	University professor	Age 4 when sister, age 2, institutionalized
Female ⁴ , Olivia	16 Sept, 2013	Parents' home	Sister	52 at time of interview	Dog trainer	Infant when sister, age 2, institutionalized

Appendix E: Parent Demographics

³denotes mother of sibling indicated in Appendix C

⁴denotes married couple, parents to siblings indicated in Appendix C

Participant	Date of Interview	Location of Interview	Relationship to Institutionalized Individual	Age at time of interview	Occupation	Comments
Male, Bertram	20 Aug, 2012	Participant's home	Father	87 at time of interview	Retired steel worker;	Four children; son institut'd age 5; involved with Association
Female, Kip	20 November, 2012	Participant's home	Mother ; daughter not institutionalized	94 at time of interview	Retired housewife	Six children; eldest had disability; not institut'd; advocate; founded schools
Female, Louise	24 January, 2013	Participant's home	Mother	85 at time of interview	Retired insurance worker	One child institut'd age 3
Female ³ , Elisabeth	23 April, 2013	Participant's home	Mother	69 at time of interview	Employed at retail	Two children; son institut'd age 7; advocate; involved in Association

Participant	Date of Interview	Location of Interview	Relationship to Institutionalized Individual	Age at time of interview	Occupation	Comments
Female, Susan	23 April, 2013	Participant's home	Mother	90 at time of interview	Retired	Four children; two had disabilities; one died, daughter institutionalized at age 8; involved in Association
Female ⁴ , Betty	16 Sept, 2013	Participant's home	Mother	83 at time of interview	Retired housewife	Four children; daughter institutionalized at age 2
Male ⁴ , Owen	16 Sept, 2013	Participant's home	Father	91 at time of interview	Retired governor of Bank of Canada	Four children; daughter institutionalized at age 2; involved for short time with Association
Female, Claire	16 Sept, 2013	Son's home	Mother; son not institutionalized	85 at time of interview	Retired graphic artist	One child, not institutionalized; advocate; involved in Association

Appendix F: Former Staff Demographics

Participant	Date of interview	Location of interview	Relationship to institution or project	Age	Occupation
Male, Joe	May 22, 2013	Work office	Former staff, HRC	45	Administrator at community agency
Male, Rory	3 July , 2013	Work office	Former staff, HRC	54	Civil servant in MCSS
Female, Wanda	28 Oct, 2013	Home	Former staff, HRC	c. 60	artist
Female, Sarah	30 Oct, 2013	Home	Former staff, HRC	c. 60	Staff at community agency

Appendix G: Key Informant Demographics

Participant	Date of interview	Location of interview	Relationship to institutionalization / deinstitutionalization process	Age at time of interview	Occupation and marital status	Comments
Female, Natalie	13 June, 2012	Agency office	Hired by community agency to facilitate deinstitutionalization from HRC	46	Social worker	Disability rights advocate
Female, Barbara	15 Nov, 2012	Participant's home	Volunteer and worker with Hamilton Assoc; advocate against institutionalization	c. 85	Retired community service worker	Started dozens of nursery schools in Ont in 60s, 70s, 80s
Male, Walter	26 April, 2013	Agency office	Legal counsel to Community Living Ontario	c. 65	Lawyer; Anglican priest	Decades of disability rights advocacy
Female, Terri	21 May, 2013	Restaurant	Advocate on behalf of deinstitutionalization; historical interest and knowledge	60+	Author, historian	Disability rights advocate

Appendix H: Interview Guide

Note: The following is a guide used for interviews for this study. As per the nature of qualitative studies, interviews were semi-structured; questions were not asked verbatim in each interview, nor were they asked in the same sequence, nor is the following list exhaustive.

The questions were categorized under three main objectives which helped the researcher to cover the major subject areas of the study in each interview. Again, this did not determine the order in which questions were asked. Questions regarding the family constellation and history, for example, usually preceded those requiring more reflection, such as ones concerning familial decision-making, the impact on the family, and understandings of disability. Further, the sections titled “*What I want to know*” are not questions that were asked of participants, but were there to guide the researcher.

Objectives

- I. Determine the predominant political, social, and economic conditions which contributed to institutionalization and deinstitutionalization practices which took place in Ontario after World War II.
- II. Explore the decision-making processes that parents of children with intellectual disabilities underwent in the decision to institutionalize their children.
- III. Explore the effects of institutionalization on family relationships and understandings of disability.

Objective I: Determine the predominant political, social, and economic conditions which contributed to institutionalization (and deinstitutionalization) practices which took place in Ontario between WWII and the present.

What I want to know:

- Who formed the Ontario governments between the Second World War and the year 2009 (when the last institution official closed)?
- In general, who were the government's supporters (i.e. who was each government trying to please)?
- What were the official government responses to intellectual disability during the periods of intense institutionalization and deinstitutionalization?
- What was happening economically in Ontario and the rest of Canada during these time periods?
- What was the predominant cultural or social understanding of disability at the peak of institutionalization?
- How did the deinstitutionalization movement originate in Ontario? How did it gain momentum?
- What are participant's recollections of neighbourhood / community before family member was institutionalized?
- What are participants' recollections of generalized understandings and interpretations of people with disabilities during this time period?

Interview Questions / Strategies

Some of this information will be gained via research at the Ontario Archives. Key sources will include but are not limited to Government of Ontario documents, historical material from Ontario institutions, and documents regarding the history and development of institutions in Ontario.

Objective I, questions for parents:

- Can you tell me a bit about the employment / income situation in your family when _____ lived at home? After s/he went to the institution?
- What can you tell me about the economic situation in general at the time?
- Do you remember how were people with disabilities were portrayed in the media during this time? How would you say they were understood by the general population during this time period? Can you give me a specific example? How would you describe disabled people's acceptability during this time period?
- Tell me a little bit about accessibility for your son / daughter before s/ he went to the institution (i.e. access to school, community events, etc.). Do you think accessibility, or lack of it, had an impact on how you cared for or made decisions on behalf of your son/ daughter?
- Can you tell me what you remember about the political situation in Ontario during your family's early life?

Objective I, questions for siblings:

- Same as above, where appropriate, and:
- Can you tell me a bit about your neighbourhood / community before your sibling left home?

Objective I, questions for survivors:

- Same as above, where appropriate
- What was life like for you in your neighbourhood before you left home?
- Did you go to school? What was that like? Can you tell me about your friends?
- Can you tell me about your family life before you went into the institution?
- Tell me about some of the things you did with your family before you moved to _____.
- Tell me a little bit about the things you did with your brothers and sisters.

Objective II: Explore the decision-making processes that parents of children with intellectual disabilities underwent in the decision to institutionalize their children.

What I want to know:

- What were the social, political, and personal forces that contributed to parents' decision-making regarding institutionalization?
- Who did the parents perceive as the primary actor in this process (i.e. parents, doctors, government)?
- Brief description and analysis of the decision-making process.
- How do participants characterize their family life before their family member went to live in an institution?

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- How did siblings interpret the decision to place their brother or sister in an institution? What did they know about the decision?
 - What do survivors know or recollect about the decision to have them placed in an institution? How do they interpret this decision?
 - For parents and siblings: how do they characterize family life while their child was living in the institution?

Objective II, questions for parents:

- Describe your family at the time of _____'s birth.
- Can you tell me a bit about _____'s birth and early years?
- Did you receive any kind of support during those years?
- What kind of support, if any, were you receiving before _____ was admitted to the institution (i.e. financial, respite care, emotional)?
- How did you explain _____'s disability to his / her siblings? Describe the process of telling _____'s siblings about his/ her disability.
- Describe some of the advice offered to you regarding _____'s care during these early years.
- In general, how would you describe your coping or management during this time period?
- Can you tell me about the steps leading up to your decision to place _____ in an institution?
- What information was shared with you that contributed to your decision? At the time, did you understand this information? Who offered information that contributed to your

decision? Who do you think was the primary decision-maker in this process (i.e. self, doctor, government, family members, etc.)?

- Describe the weeks immediately before and immediately after _____ went to the institution.
- How do you think _____'s brothers and sisters interpreted / felt about _____ going to an institution? How did you explain this decision to them?

Objective II, questions for siblings

- Describe briefly what you remember about your family life before _____ went to the institution.
- Can you tell me a bit about being a sibling of _____ in those early years?
- What do you remember about his / her care? Do you remember your parents discussing _____'s care?
- Were you aware of other people's involvement in _____'s care? Can you describe this to me?
- Describe what you knew about decisions being made to place _____ in an institution. Was this discussed? Did you know this was a potential development? Did you talk about this with anyone (i.e. friend, classmate, sibling, relative, parents, etc.)?
- Briefly describe the events surrounding _____'s move to the institution.

Objective II, questions for survivors:

- What can you tell me about your family's decision to have you move to ____? Did you know your family was considering having you move? Can you tell me a little bit about how this was explained to you?
- How did it feel when your parents told you that they had decided to have you move to ____? Can you tell me about the move?

Objective III: Explore the effects of institutionalization on family relationships and understandings of disability.

What I want to know:

- What effect did the absence of a family member have on relationships and family life and on understandings of disability?
- How did families live out their relationships with each other after one member of the family was institutionalized?
- What are participants' understandings of family after having experienced the institutionalization process?
- In general, how would participants characterize or describe its effect on them? On their families? On family life?

Objective III, questions for parents:

- Briefly describe the history of ____'s stay at ____ (institution).

-
- Describe the visits you paid to _____ after he was admitted to the institution (i.e. regular, irregular, frequent, infrequent, with other family members, alone, etc.). Who would you say was the primary actor in deciding when or how frequently those visits would be made (i.e. the institution decided; parents determined visit schedule, etc.)?
 - How did you celebrate family events in _____'s absence (i.e. birthdays, deaths, births, weddings, etc.)?
 - In your opinion, who directed his/ her care while s/he was in the institution (i.e. staff, family doctor, doctor at the institution, parents)?
 - In general, how would you describe your relationship to _____ while s/he lived in the institution?
 - In general, how would you describe your other children's relationship with _____ during this time?
 - Did you speak about _____ at home while s/he was living at the institution?
 - Briefly describe the deinstitutionalization process that _____ went through.
 - Did your relationship with _____ change when he moved out of the institution? How?
 - Do you think the relationship between _____ and your other children changed at this time? How?
 - Has your understanding of disability changed from the time when _____ entered the institution until now? How?
 - In general, what would you say was the effect of institutionalization on your family life? On you, personally?

Objective III, questions for siblings:

- Tell me what you remember about the time period of your sibling's institutionalization.
- Briefly describe your home life during this period. Did home life change after _____ went to the institution? How?
- Was _____ mentioned at home? Did h/she come home to visit?
- Did you visit _____ at (institution)? What can you tell me about those visits?
- What effect did _____'s leaving have on you and your siblings?
- What effect, if any, did _____'s departure have on your relationship with your parents? your other siblings?
- In general, how would you describe your relationship with _____ during the period of institutionalization?
- Briefly describe the deinstitutionalization process _____ went through.
- Has your relationship with _____ shifted from the time h/she was institutionalized until now? How? How would you describe your current relationship with _____?
- Has your understanding of disability changed from the time of _____'s institutionalization until now? How?
- In general, what would you say was the effect of institutionalization on your family life? On you, personally?

Objective III, questions for survivors:

- *Only if participant is willing:* Can you tell me a bit about your time at _____? How long were you there? Can you tell me a bit about your daily / weekly routine?

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- Did your family come to visit you? Tell me about those visits. How often? Who came?
 - How did those visits make you feel (use face symbols for the four basic emotions—happy, sad, angry, scared, if needed)?
 - Did you ever go home to visit your family? When? Can you tell me a bit about those visits? How long would you stay at home? What kinds of things would you do together? How would those visits home make you feel?
 - Overall, how would you describe your time at (institution)?
 - Did your relationship with your family change during the years that you spent at the institution? How?
 - Do you see anyone in your family now? Do you ever talk about your time in the institution with them? What kinds of things do you do with your family now?

Interview Questions for former staff at provincial institutions

Information obtained from this group of people will primarily meet Objective III: explore the effects of institutionalization on family relationships and understandings of disability.

What I want to know:

- In general, what was life like inside the institution?
- What are workers' perspectives of the impact of institutionalization on family relationships?
- How would workers characterize or describe relationships between institutionalized people and the rest of their family?

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- Did their roles or relationships with institutionalized individuals shift when family members were present?

Questions for former staff:

- Can you tell me a little bit about your time spent working at the institution?
- Did you interact with the families of the people who lived at the institution? Can you tell me a bit about that?
- Can you tell me a bit about how visits were conducted at the institution (i.e. what were some of the rules and regulations governing how visits were carried out)?
- Did families come to visit their family members in the institution? What can you tell me about those visits?
- Did people living in the institution go home to visit their families?
- Do you think that the relationships between workers and institutionalized individuals shifted when family was present? If so, how?
- Do you think that families' understandings of disability shifted during the time that their family member was institutionalized? If so, how?
- Can you tell me a little bit about the deinstitutionalization process? Did you notice a shift in family relationships or understandings of disability during the deinstitutionalization phase?
- In general, how would you say that institutionalization affected family relationships?

Interview questions for key informants:

Information obtained from this group provided information for all three objectives, depending on their professional and personal experience.

Questions for key informants:

- Tell me what you know about the social and political situation in Ontario in the decades after World War II, particularly as it relates to institutionalization.
- How were you involved with institutionalization/ deinstitutionalization?
- What would you say were the primary forces encouraging families to place their children in institutions? What were the forces that contributed to the deinstitutionalization movement?
- What do you think was the impact of institutionalization on families?
- Do you think that people's understandings and interpretations of disability have shifted in the decades since institutionalization was at its peak? How?
- What are your understandings of the kind of care that institutionalized people received?